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DOCTOR OF PHILOSOPHY

Making sense of acute leukaemia:

an interpretative phenomenological analysis of the experiences of patients and family caregivers

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family caregivers*

Constantina Papadopoulou

2014

University of Dundee

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Making Sense of Acute Leukaemia:
An Interpretative Phenomenological Analysis of the
Experiences of Patients and Family Caregivers

Thesis submitted for the Degree of Doctor of Philosophy

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Abbreviations

AML	Acute Myeloid Leukaemia
ALL	Acute Lymphoblastic Leukaemia
ALS	Amyotrophic Lateral Sclerosis
APML	Acute Pro-Myeloid Leukaemia
BMT	Bone Marrow Transplantation
COPD	Chronic Obstructive Pulmonary Disease
GP	General Practitioner
HIV/ AIDS	Human immunodeficiency virus infection
IPA	Interpretative Phenomenological Analysis
MS	Multiple Sclerosis
QOL	Quality of Life
R & D	Research and Development
REC	Research Ethics Committee

Publications

- Papadopoulou C., Johnston B., Themessl-Huber M. The experience of acute leukaemia in adult patients: A qualitative thematic synthesis. *Eur J Oncol Nurs.* 2013; 17(5): 640-648, doi: <http://dx.doi.org/10.1016/j.ejon.2013.06.009>.

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One of the first workshops I attended during the course of my PhD started off by comparing the PhD experience with a ride on a roller coaster. And this was true to a certain extent. However, the presenter did not specify what type of roller coaster: a 'Kiddie coaster', a 'Giga coaster' or a 'Strata coaster'? Well, I was prepared for a comfortable ride on a Kiddie coaster with the occasional up and down, and it turned out to be a Strata coaster (drop over 120 metres and completing a full circuit)! And I would not have come through to the end of the ride had I not received the support of the many mentioned hereafter.

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Declaration

Candidate's Declaration

- (i) I, Constantina Papadopoulou, hereby certify that I am the author of the present thesis; that, unless otherwise stated, all references stated have been consulted by me; that the work of which the thesis is a record has been done by me; and that the thesis has not been submitted in any previous applications for a higher degree.

Date.....

Candidate's Signature.....

Supervisors' Declaration

- (ii) We hereby certify that the candidate has fulfilled the conditions of the relevant Ordinance, and Regulations of the University of Dundee, and that as such the candidate is eligible to submit the following thesis in application for the degree of Doctor of Philosophy.

Date.....

Supervisor's Signature.....

Date.....

Supervisor's Signature.....

Date.....

Supervisor's Signature.....

Abstract

Background and objectives: Living with acute leukaemia can challenge patients' physical, emotional and psychological well-being and functioning, but can be a greatly challenging experience for their families, too. Such a life-changing experience can potentially initiate or accelerate a meaning-making process that may be prolonged and demanding. Yet, there is a dearth of empirical evidence with regard to how adult patients with acute leukaemia or their family carers make sense of their illness-related experiences, and, as a consequence, clinicians still lack the knowledge necessary to tailor support to this specific population. Therefore, this qualitative study aimed to explore the processes, through which patients and family caregivers construct their meanings of acute leukaemia.

Design and methods: An exploratory design was employed using serial, in-depth interviews, guided by Smith's Interpretative Phenomenological Analysis approach. Ten adult (>18 years of age) patients with acute leukaemia and eight patient-nominated family caregivers were recruited during a 14-month period from two clinical NHS sites in Scotland. Two serial interviews were conducted with each participant, two to four weeks apart, within the first year of diagnosis or post-relapse. In total, thirty-six interviews were analysed.

Results: Findings deriving from patient interviews indicated that acute leukaemia creates a state of imbalance to the person, which may initiate a search for a new equilibrium. Patients' journeys towards making sense of their illness may involve three inter-changeable processes: *decay*, *transformation* and *growth*. As patients learned of their diagnosis and their treatment commenced, a sense of decay dominated their lives. 'Feeling like being a prisoner' and 'living with an impaired self' were two common emergent themes. Running in parallel, signs of transformation started to become more evident as time elapsed. Within the third making-sense process, that is to say growth, themes such as strengthened family bonds, and reprioritising values were among the most prominent. Carers' accounts of their indirect cancer experience revealed that family members made sense of their acute leukaemia-related situation as a state of limbo that was conceptualised as a maze. After being *thrust into limbo*, the invisible nature of acute leukaemia created difficulties for carers to conceptualise it; however, they experienced its impact on their lives quite hastily. In order to *navigate limbo*, carers had to learn to steer through their social world and the unfamiliar hospital environment and eventually manage to *transcend limbo* by employing various coping strategies, by

facilitating the cancer journey of their loved ones, and finally, by reconciling with the patient's illness.

Conclusions and future implications: Findings of this contextually and methodologically novel study highlight the complex nature of sense-making for both patients and family caregivers experiencing acute leukaemia. Additional research is warranted to further uncover the various ways in which meaning is initially constructed, negotiated, re-visited and reformed as patients and/or family carers go through the different phases of living with the illness. In any case, clinicians can rely on the findings of the present study in order to provide on-going support and guidance so that patients and carers visualise the 'invisible' acute leukaemia and make sense of their illness-related situation in ways that favour their short- and long-term psychosocial adjustment.

PREFACE & RATIONALE FOR THE THESIS

‘Lena’

I had been working as a staff nurse for two months when I first met Lena. I can still recall the state of arousal in the Oncology ward the day she was admitted for her relapsed acute leukaemia. “She’s back again,” the Sister Nurse had said, and I remember the look on her face, fear mixed with worry and a sense of resignation to the fact that yet another patient had returned with a relapsed illness. “Who is she?” I asked. “Lena,” she replied.

Lena had received her diagnosis of acute leukaemia three years before and, after receiving one round of chemotherapy, her leukaemia relapsed and she was subsequently treated with a bone marrow transplant. That day, a year and a half later, her leukaemia had relapsed again and she was re-admitted to the same ward for another round of chemotherapy. Lena had a ‘reputation’ in the ward; she was perceived as having a ‘difficult’, distant persona. Her oldest brother had died of leukaemia several years before.

Our first encounter was not ordinary; perhaps the term ‘awkward’ is a better fit. She was put in one of the four-bedded rooms of the ward and her previous experience there was the reason for her putting up a ‘firewall’ of curtains. I went on to start her intravenous (i.v.) chemotherapy, built up my confidence and pulled back the curtain. She looked at me with contempt: “You’re new, I haven’t seen you here before.” “Yes, I’m Constantina and I will be in charge of your treatment today,” I mumbled. She declined the offer of any information regarding the procedure – a ritual I would perform with any patient receiving chemotherapy, irrespective of how many times they have received treatment before. After calibrating the pump and checking her intravenous catheter, I left. And that was our first not-so-warm encounter.

Despite her initial coldness, Lena was the first patient that challenged our skills and abilities as nurses in a profound way. Gradually, we pulled together our forces and started working a team; it was thanks to her. And as time passed, Lena created strong bonds with the whole nursing team. We laughed together; we had discussions together; we accompanied her and her family in her leukaemia journey. Her leukaemia went into remission again for a short period of time only to relapse for a third and final time. Two weeks before her death, when her condition started to deteriorate, during my night shift she broke into tears: “Thank you all, I was afraid I would die alone, yet you’ve all been like daughters to me; you cared for me and my family ...” The morning of her death all the members of the team were informed, some came to help

prepare her body and many attended her funeral. Lena's death was one of the hardest I had to deal with, as I had accompanied her in the various different stages of her acute leukaemia journey.

Lena was only one of the many patients I have encountered; one of the many patients who, along with their families, offered invaluable lessons, both to me and my colleagues. Each patient and each family member carried a unique life story and each had a slightly different perception of the illness bound by one common element: acute leukaemia; an invasive illness that equally affects patients and their loved ones. All of them have contributed to my professional and personal development, and they have eventually contributed to the inception of this PhD study. They were my compass and I trust that they will always be the starting and concluding point of my career as a researcher.

Background to the thesis

Leukaemia refers to a group of clonal disorders characterised by accumulation and impaired differentiation of blood cells in the bone marrow [1, 2]. Broadly, there are two types of leukaemia, acute and chronic, that are further divided into subtypes according to the affected cell line. Patients diagnosed with acute leukaemia require intensive chemotherapy treatment that needs to start immediately after diagnosis. This treatment is usually administered in a hospital setting, spans a period of several months and has predominantly curative intent. In this sense, acute leukaemia differs from chronic. The initial stages of the latter, although not considered treatable, involve a 'watchful waiting regimen' with prolonged administration of biological treatment (i.e. monoclonal antibodies) that patients receive on an outpatient basis [3]. The treatment of chronic leukaemia aims to induce remission of the illness; however, a relapse is inevitable. Patients can build up tolerance to the agents and, therefore, may have shorter intermittent periods of remission [3]. These differences between acute and chronic leukaemia in both the management of the disease and the illness trajectory, suggest the possibility of a distinct illness experience on the part of the patients and their loved ones. This PhD thesis is focussed on the experiences and meaning-making processes of adult patients with acute leukaemia and their family caregivers. This acute and life-threatening condition, along with the rapid changes taking place (on a physical and social level), particularly at the early stages of the illness, often disproportionately increases the patient's levels of distress and needs [4]. Hence, the requirement for multidisciplinary teams to provide on-going patient-centred and person-tailored care is pressing.

Seldom do patients with haematological malignancies go through the experience of illness alone. Throughout the cancer trajectory, family caregivers provide a significant amount of support to patients, juggling this with a host of other different tasks and roles [5, 6]. A caregiver is a person 'who shares' the cancer experience with the patient; a person who provides support and sustenance [7]. This person can be either a family member, a partner or even someone 'considered as family' by the patient [8]. Extensive research in health and social care has shown that caring is connected with a wide variety of social meanings, factors and processes [7]. Caregivers can affect the patients' positive adaptation related to their disease as they are a vital component of patients' experience and can also mediate patients' perspectives on cancer [9]. Therefore, promoting the quality of life (QOL) of caregivers of patients with cancer should be in the agenda of healthcare providers [10]. In the context of acute leukaemia, however, research focussing on the perspectives of family caregivers is scant.

How individuals make sense of significant and/or stressful events has been examined, to a certain extent, in different healthcare contexts [11]. When facing negative events that challenge people's existing construction of the world, individuals will attempt to integrate their experiences – the ones of order and the ones of stress – in a new meaningful reality through a meaning-making process [11-13]. A life-altering and life-threatening disease such as cancer forces those people affected – both patients and their significant others caring for them – to re-evaluate their lives through the prism of their current situation. Frequently, this is followed by a (sub-) conscious attempt to seek and possibly create new meaning of a host of their illness-related experiences. Examining how people construct meaning in different contexts is worth pursuing because it is related to coping mechanisms [11, 14]. This PhD thesis focusses on the processes patients with acute leukaemia use in order to make sense of the illness, as well as how family caregivers make sense of the illness of their loved ones.

Research interest and clinical importance

This PhD thesis is derived from the researcher's personal interest in how adult patients and their family caregivers make sense of an acute and invasive illness such as acute leukaemia. This population has not received much research attention, except perhaps for their participation in testing drug efficiency in clinical trials. In fact, more often than not, patients with acute leukaemia are enrolled into drug trials as soon as they enter the healthcare system. However, their needs develop and increase almost exponentially at the initial stages of the illness journey and then at significant milestones (including remission, follow-up period,

relapse, and possible bone marrow transplantation), and little empirical evidence exists regarding their personal experiences of the illness or how they make sense of it. By adopting an interpretative phenomenological analysis approach, this PhD thesis offers a close focus on the experiences and the meaning-making processes patients and family caregivers adopt. It is hoped that the present study will stimulate further research for the future development of tailored interventions to facilitate patients and their families in their making-sense processes in the context of acute leukaemia. In addition, this PhD thesis will reinforce the strong requirement for adequate and on-going support that needs to be provided by clinicians so that patients and carers understand acute leukaemia and make sense of their illness-related situation, which, in turn, can facilitate their short- and long-term psychosocial adjustment.

Overview of chapters

The thesis consists of seven chapters; the two first chapters provide a comprehensive review of the literature and the subsequent five are dedicated to the research project conducted as part of the present PhD thesis. An overview is provided here:

- ❖ In Chapter 1, the evidence regarding the experience of living with acute leukaemia is visited from the perspectives of adult patients and their family caregivers. The Chapter begins by briefly providing leukaemia's demographic and clinical profile, including incidence, prevalence and mortality rates, as well as treatment-related information. Following an overview of illness-related experiences, the literature regarding the experience of adult patients with acute leukaemia is presented in a meta-synthesis of qualitative evidence. Next, drawing upon a conceptual model of the cancer family caregiving experience [15], the literature on family caregivers in the wider cancer context is presented. The dearth of published research that includes family caregivers of patients with acute leukaemia is stressed. The Chapter concludes with an appraisal of the existing body of evidence in both groups, highlighting current research gaps.
- ❖ Chapter 2 focusses on the literature regarding the concept of 'making sense'. The integrating 'meaning-making model' from Park and Folkman [11, 14] is described first. Findings from a systematic review of the literature regarding 'making-sense' processes in the context of cancer are presented from both the patient and the caregiver's perspective. Finally, an appraisal of the available evidence is pursued that discusses the

gaps in current literature, thus revealing the unexplored territory of 'making sense' in the context of acute leukaemia.

- ❖ Chapter 3 begins with a discussion of the main issues presented in the previous two chapters and introduces the research problem that this study will address. Following this, the literature pertaining to the selected methods is explicitly detailed. The ontological, epistemological and axiological stances underpinning the current project are explained. An overview of the numerous possible qualitative methodological approaches, along with reasons for rejecting them, is offered. The selected approach, Interpretative Phenomenological Analysis, is then presented in detail in the context of wider phenomenology.
- ❖ In Chapter 4, the aim and research questions of the current project are stated. The chapter goes on to describe the steps and procedures that were followed while conducting the study. This includes the sampling strategy, participants' eligibility criteria, data collection procedures and ethical considerations pertaining to the project. The Chapter concludes with a detailed presentation of the steps followed during the data analysis process.
- ❖ Chapter 5 presents the first part of this study's findings that derived from the analysis of interviews with patients. Analysis of the patient dataset revealed three making-sense processes: decay, transformation and growth. Through an explicit account of all subordinate emerging themes, these processes are analytically presented, thus offering points of convergence across different participants.
- ❖ Chapter 6 concentrates on the second part of this study's findings that were derived through analysis of the family caregivers' dataset. Three different 'making sense' processes were identified: entering, navigating and transcending a state of limbo, the whole of which was conceptualised as a maze. Similarly to the analysis of patient data, the three processes of making sense identified for family caregivers are presented again in conjunction with the subordinate themes they are consisted of by offering points of convergence across different participants.
- ❖ Finally, Chapter 7 critically discusses the important findings and implications of the current study. Findings for both groups are respectively linked with the existing and wider cancer context literature. The strengths and limitations of the current study are examined in the following section. The Chapter concludes with implications for clinical practice and suggestions for future research.

CHAPTER 1 – Living with acute leukaemia

1.1. Introduction

This chapter starts off with a brief presentation of the profile of leukaemia, its epidemiology and management. An overview of the existing literature on adult patients with acute leukaemia is provided and main issues that researchers have addressed in this population are summarised. To highlight what is currently known regarding the experience of acute leukaemia from the patients' perspectives, a focus is placed on evidence from studies utilising qualitative methodology, presenting the results in a qualitative meta-synthesis. Also, the existing literature on family caregivers is discussed; first in the wider context of cancer and subsequently in the context of haematological malignancies and acute leukaemia in particular. The chapter concludes with an overall appraisal of the literature to highlight current issues, limitations and gaps.

1.2. The experience of acute leukaemia – the patient perspective

Acute leukaemia can arise across the lifespan, in those in childhood to older individuals [16]; however, this PhD thesis focusses on the experience of adult patients with acute leukaemia. Once diagnosed with acute leukaemia, patients undergo lifesaving, intensive, in-patient treatment that requires prolonged hospitalisation periods [3], and along with the treatment they are called to face a host of different challenges. These challenges are the focus of the current section.

1.2.1 Leukaemia: facts and figures

Leukaemia refers to a group of disorders characterised by an accumulation of white blood cells in the blood and bone marrow [17]. These benign cells can cause symptoms, either because of

bone marrow failure (including anaemia, neutropenia and thrombocytopenia) or due to organ infiltration (liver, spleen, lymph nodes, brain, for example). The group is classified into four main categories, acute and chronic, which in turn are further divided to lymphoblastic and myeloid [16, 17]. These disorders were originally termed acute or chronic based on life expectancy, but now they are classified according to cellular maturity. Acute leukaemia is defined when over 20% of the bone marrow or the blood consists of blast cells. Specifically, acute leukaemia is characterised by an increase in the number of myeloid cells or lymphocytes in the bone marrow and an arrest in their maturation, resulting in haemopoietic insufficiency with or without leucocytosis [1, 2]. There are two main types of acute leukaemia: acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML) [1, 2, 16]. Differentiation between the two types is essential for the decision of treatment and is also a prognostic determinant [17]. AML is the most common form of acute leukaemia in adults and its incidence increases with age [1, 18]. ALL is the most common form of leukaemia in childhood, with a secondary increase after the age of 40 years [1, 18]. The exact cause of leukaemia remains unknown; however, a combination of environmental factors (e.g. chemical toxins, radiation, cytotoxic agents) and genetic predisposition (e.g. chromosomal rearrangements) have been proposed to play a role in increasing the risk of developing leukaemia [16, 17].

Latest worldwide incidence rates for all types of leukaemia are estimated at 350,434 new cases, while there are approximately 257,000 leukaemia-related deaths [19]. Specifically in UK, leukaemia represents around 2.5% of all diagnosed cancers [18]. In the UK in 2010, there were 8,257 new cases of leukaemia and 4,504 deaths from leukaemia registered [18]. Leukaemia is the ninth most common cause of death from cancer in the UK [18]. Overall, leukaemia is more common in men than women [18, 20]. Although leukaemia is the most common cancer of childhood, more than nine out of ten cases are diagnosed in adults [18]. The latest rates show that around a third (33%) of patients with leukaemia survive their disease beyond ten years, compared to less than 10% in the early 1970s [21]. The advancements in treatment, molecular profiling and supportive care of leukaemia have increased overall: 1-year survival to 64.5%; and 5-year survival to 44% of all diagnosed cases [1, 2].

The primary objective of the treatment of acute leukaemia is to achieve complete remission that is less than 5% of blast cells in bone marrow, normal peripheral blood count and no other symptoms or signs of the disease [1, 17]. Initial chemotherapy is known as the induction phase and is administered in cycles allowing time for the marrow to recover [1, 22]. There are several chemotherapy cycles in the induction phase and then the consolidation or post-remission phase follows, consisting of another sequence of chemotherapy [1, 22]. The entire treatment lasts several months. The management of acute leukaemia has seen great improvement over

the last 40 years. This was mainly due to developments in specific treatments and support therapy [16, 22].

AML is largely treated according to established protocols or current Medical Research Council trials. At the moment the AML-17 trial is used for all subtypes of AML, except for acute promyelocytic leukaemia [23]. The most commonly used chemotherapy drugs are: cytosine arabinoside (in high or conventional doses), fludarabine, idarubicin, mitoxantrone, etoposide and gemtuzumab [1]. In ALL, the regimen protocols differ from those in AML, according to each case and the protocol followed by the healthcare team. In general, steroids, vincristine, l-asparaginase and cytosine arabinoside, are the most frequently used agents [17]. All these agents are myelotoxic with minor selectivity between normal and leukaemic cells, thus resulting in severe marrow failure that requires prolonged and intensive supportive care [17]. The support therapy for bone marrow failure includes the insertion of a central venous catheter, blood product support, haemostatic support, antiemetic treatment, prophylaxis and treatment of infection, nutritional support, reproductive measures and pain medication [17, 22].

Transplantation for patients with leukaemia is not the first line treatment option [16]. Bone marrow transplantation (BMT) is still associated with high mortality rates, with the threat of relapse or even the development of a secondary malignancy remaining possible [1, 17]. Allogeneic stem cell transplantation is indicated for patients with ALL, performed in the first remission and actually can lead to a long-term survival of 40% [1, 17]. In AML, allogeneic transplantation is a consideration for suitable patients under the age of 60 and with minimal co-morbidity [1, 17]. Autologous transplantation in both AML and ALL is thought to reduce the rate of relapse, but again, there are studies showing little benefit of this treatment to overall survival [1, 17, 22].

1.2.2 A multitude of patient outcomes

Because patients with acute leukaemia require prolonged and intensive chemotherapy treatment in the hospital, the impact of their illness on their lives can be profound. Living with acute leukaemia can challenge patients' physical, emotional and psychological well-being and functioning. Indeed, fluctuations in quality of life (QOL) [4, 24-31], symptom experience [30, 32-37], and psychosocial impact [25, 38-52] have been shown at various time-points during the cancer journey, predominantly at diagnosis and in the context of BMT.

Published in 2004, a scoping review of studies conducted within the previous decade, attempted to summarise the short- and long-term effects of AML on health-related QOL [4]. Despite wide variability in study sample demographic characteristics and time periods investigated, findings derived from this body of early studies indicated that the most affected life domains included physical and psychological well-being as well as emotional and sexual functioning [4]. In particular, the QOL of patients with AML was influenced by fatigue, emotional functioning and appetite loss [35]. Despite the adverse effects of the illness itself and its treatment, the authors postulated that long-term survivors of AML seemed to recover almost in full [4]. Whether such trends are indeed true, irrespective of type of haematological malignancy, or whether these adverse effects are shared among individuals with specific haematological cancers, is yet to be confidently confirmed. Indeed, whereas improvement in the majority of the QOL domains during the course of treatment for AML [31] as well as full recovery among patients with various haematological malignancies three years after BMT [25] were shown, Persson et al. [30] found that patients with acute leukaemia were significantly more affected in their role ($p<0.05$) and social functioning ($p<0.01$) than patients with malignant lymphoma throughout the two years of investigation after treatment initiation. However, global QOL and physical functioning showed greater improvement over the two years for patients with acute leukaemia rather than for those with lymphoma. Conversely, when QOL after the in-patient period and during outpatient treatment was compared, researchers found no further significant changes [30]. Moreover, the burden that specific treatment modalities might bring to patients with acute leukaemia has been proposed as a potential factor for impaired QOL. A relatively recent study in a large sample of survivors of acute leukaemia ($n=419$) concluded that patients who received BMT seemed to be more affected after the 5-year survival period than patients receiving conventional treatment (i.e. intensive chemotherapy) [26]. Compared to conventional therapy, transplantation was related to significantly worse long-term impact on QOL with domains including leisure time activities, social life, financial management and sexuality being affected [26]. However, potential reasons for such differences remained unexplained. One study compared the meaning of QOL between patients with acute and those with chronic leukaemia [47]. Patients with acute leukaemia perceived QOL as a positive attitude towards life while patients with chronic leukaemia perceived it as life satisfaction. In this secondary analysis, it is evident that patients with acute leukaemia experience uncertainty differently as opposed to those diagnosed with chronic leukaemia [47]. For patients with acute leukaemia, the feeling of uncertainty was mixed with a sense of immediate life threat, whereas it transformed into a vague prolonged life threat for those living with chronic leukaemia. Patients may rely on their families and healthcare professionals for support, but their main concerns revolve around regaining normality and still

reflect uncertainty about the future [47]. In any case, assessing a person's QOL has been recognised as a subjective process that can be influenced by cognitive and emotional factors. This notion was partly supported by a study conducted in elderly patients with AML [28], where patients' self-reported QOL was not in agreement with the patients' performance status as assessed by clinicians. In addition, those patients who gave poorer QOL scores still had shorter survival even though they were evaluated with favourable performance status scores [28].

Researchers have also investigated the symptom experience of patients with acute leukaemia throughout the illness trajectory. They have done so, however, in small-scale studies [35-37, 53, 54] and also in studies where the patients' experience of symptoms was documented/explored as a secondary control variable for health-related QOL rather than as the primary study outcome [24, 27-30, 35, 53, 55, 56]. Despite wide variability in the measurement of symptom prevalence, severity and/or distress, as well as characteristics of study samples, collective evidence suggests that lack of energy/fatigue [30, 35-37, 56], lack of appetite [36, 37], sleep disturbances [30, 36, 37], pyrexia [36, 56], nausea [36], dry mouth [37, 56] and pain [37] may be among the most frequently and consistently experienced symptoms in patients with acute leukaemia during the active phases treatment. Moreover, weakness/fatigue [36, 37, 55], difficulty sleeping [36, 37], pyrexia [36] and pain [37] may also constitute the four most severe and distressing symptoms at this stage of the illness trajectory. Still, the current body of knowledge remains limited while the relative risk imposed by demographic, clinical or biological characteristics of individuals is unknown. Nonetheless, a few recent efforts have been reported that aimed to alleviate symptom burden by offering exercise interventions [32-34, 57, 58]; despite some encouraging improvements in symptoms such as fatigue, additional research is required to target additional prevalent and/or severe symptoms as the ones mentioned above.

The psychosocial impact of acute leukaemia has also been explored in a number of methodologically diverse studies and in different contexts of treatment [25, 40, 43, 45, 46]. Such studies have predominantly focussed on examining the psychological repercussions (e.g. emotional distress, hopelessness, meaning) and social impact (e.g. utilisation of coping strategies, availability of social support) associated with living a life with acute leukaemia. Despite current evidence still being limited, findings from these studies offer some indication of the magnitude and nature of the psychosocial burden experienced by this patient population. In terms of emotional functioning, results from a recent study showed that patients with acute leukaemia may suffer from post-traumatic stress disorder [43], and preliminary evidence suggests that clinically significant symptoms of traumatic stress

(including dissociation, anxiety, hyperarousal) may be prevalent in one-third of this population [43]. Patients may also report existential problems that may be associated with reduced psychological and sexual energy, low sense of coherence and increased need for intimate help and counselling [46]. Interestingly, there seems to be a positive relationship between perception of time and psychological distress in this population [45]. This association might mean that when patients are diagnosed with a life-threatening illness and experience high levels of anxiety they also experience an altered sense of time, which can be interpreted as a sign of mental suffering [45]. In addition, increased psychological distress early into the acute leukaemia journey may be predictive of additional burden as time elapses. Indeed, survivors who reported anticipatory distress before infusion were more likely to have more anxiety and depressive symptoms later [40]. In the context of BMT, patients' psychological status prior to transplantation was found to be predictive of the psychological distress experienced in the three-year period following BMT [25]. The effects of the patients' demographic characteristics might play a role in the expression and fluctuations of psychological distress over time. Factors such as age and educational background have been examined to this end. In an early study of survivors of acute leukaemia, patients of a younger age and lower educational level were found to be more susceptible to psychological distress 5 years after the end of their treatment [40].

Closely related to patients' psychological adaptation to living with acute leukaemia, researchers have attempted to explore the meaning patients construct of the illness and its treatment. In his early work, Steeves suggested that for patients with leukaemia undergoing BMT, the quest for meaning starts with negotiating their new social position [51]. Meaning was constructed through three different approaches: relying on 'superstition', relying on 'mathematical odds' and fate, and appealing to a higher order through altruism and religion [51]. These findings were further supported by additional evidence suggesting that, as patients negotiated the period from diagnosis to treatment and then survival, they brought their personal life values and a life-long pattern of dealing with adversity into their confrontation with a life-threatening illness [52]. This finding is in agreement with the idea that the way a person engages with cancer is part of a pre-existing conceptual model that people use to explain difficulties happening in their lives [8]. Results from another study suggested that survivors may perceive their illness as a 'spiritual journey' and may experience positive changes in relation to their personhood and more generally in their life by benefit-finding [50]. Whether these changes, however, were also linked to the psychological functioning of patients, remains unclear.

A link between the use of coping strategies and/or receipt of social support and survival rates has been proposed; however, these results can be seen as preliminary only. Andrykowski et al. [59] found that attitudes towards cancer characterised by 'anxious preoccupation', as well as lower functional QOL levels were associated with poorer survival in 42 patients after BMT. Among patients with leukaemia (acute and chronic) who were admitted for allogeneic BMT and were followed-up for a period of five years, positive links between survival and distraction and between survival and fighting spirit were proposed by two consecutive studies from the same research group [44, 60]. Emotional support, acceptance and taking control were also positively, while compensation was negatively, associated with survival [60]. Supporting these results, Molassiotis et al. [61] found that shorter survival correlated with specific personality characteristics, such as being less hopeful and exhibiting more passive behaviour.

Irrespective of its potential links to survival, the concept of hope has also been invariably explored in qualitative studies in the context of adjustment to life with a haematological malignancy. An early study showed that maintaining hope during BMT was seen as a dual action process: dealing with leukaemia and at the same time keeping it in its place [48]. Affirming relationships and staying positive were described as important strategies used by patients during BMT in an attempt to boost hope [62]. To this end, the 'writing of a positive story' to maintain courage during BMT was also proposed [63]. By using field observations and interviewing patients and nurses, researchers concluded that this 'writing of a positive story' was a constant process that required laborious effort of thinking, reasoning and acting [63]. During this process and as patients embarked on this demanding journey to maintain their courage and make their belief in a happy ending become true, the period of aplasia was regarded as the most challenging phase. While to a certain extent such findings propose an active attempt to deal with illness and treatment challenges through hope, whether hope fluctuates during transitions or exchanged with feelings of despair within this demanding process remains ambiguous. Moreover, whether such findings are readily applicable to patients with acute leukaemia can also be questioned.

1.2.3 A qualitative thematic synthesis of the experience of acute leukaemia in adult patients

Based on evidence presented in the previous Section, certain research drawbacks and gaps in the literature exist, including (a) a focus on certain domains (such as QOL) while others are significantly understudied (such as symptom experience and meaning-making processes), (b)

limited sample sizes, (c) studies including samples of patients with mixed haematological malignancies that pose difficulties in differentiating results and possibly making comparisons, and (d) most of the research being cross-sectional, thus lacking the necessary depth that could allow for directionality in relationships. Therefore, more in-depth exploratory research is warranted to help clarify certain elements regarding specifically the experience of acute leukaemia. For this reason this Section moves on to synthesise evidence from qualitative research carried out with patients with acute leukaemia during intensive chemotherapy and in the context of BMT.

Synthesising evidence deriving from primary qualitative studies has the potential to provide a more in-depth and coherent understanding of patients' experiences [64-67]. To achieve this goal, a meta-synthesis of qualitative evidence on how adult patients diagnosed with acute leukaemia experience living with their illness was conducted in order to answer the research question: *What does the experience of acute leukaemia entail in adult patients?* Excerpts of this qualitative meta-synthesis have been published in a peer-reviewed journal and appear in Papadopoulou et al. [68] (Appendix 1).

In order to locate the relevant literature, a systematic search strategy was devised and run in seven electronic databases: Medline, CINAHL, EMBASE, PsychINFO, BNI & archive, SSCI and ASSIA. The search strategy consisted of two strings combining free text terms, thesaurus terms and broad-based terms [65]: one for qualitative methods, based on the Rochester qualitative filter adapted by Jones [69] and one for acute leukaemia, created initially for Medline and then adapted for the rest of the databases. The search strategy can be found in Appendix 2.

Papers were included in the study if the following criteria applied:

1. Studies using qualitative methods to elicit patients' in-depth experiences of acute leukaemia.
2. Study samples of adult patients (>18 years of age) diagnosed with acute leukaemia.
3. Published in peer reviewed journals.
4. Time period: 01/1990 to 01/2013 (updated from 10/2010-01/2013).
5. English language.

Due to time constraints, grey literature, conference abstracts and thesis dissertations were excluded from this review.

The electronic search was initially conducted in November 2010; however, in order to keep the synthesis up-to-date with research being conducted, the search was repeated in 01/02/2013

to identify new studies published until January 2013. Aggregated results from both searches are reported in Papadopoulou et al. [68]. The search yielded 15,125 papers. Following the screening process, the final sample consisted of seven original articles reporting six studies conducted exclusively with patients with acute leukaemia [70-76]. Two additional studies were added to the final sample, where at least 75% of the sample were patients with acute leukaemia [77, 78]. The reference lists from the ten included studies were then hand-searched. Further searches were conducted across all seven databases using the authors' names from the ten relevant papers as keywords. Additionally, archive, hand searches were performed in three selected journals (*Leukaemia Research*, *Psycho-oncology*, *Qualitative Health Research*). Finally, authors from the included studies were contacted by email and asked if they were aware of any other relevant studies or if any relevant papers were in press. None of these additional search strategies yielded new articles.

The next issue to address was how to appraise the quality of the retrieved studies. As there is no consensus on a list of criteria by which to appraise qualitative evidence, three different methods were employed to enhance rigour: a guide proposed for reading qualitative articles [79], a validated scoring system [80] and a typology for classifying findings [79]. A summary of the appraising tools is provided in *Table 1.1* and more detailed versions of these can be found in Appendix 3. All papers were considered to be of reasonable methodological quality and included in the final synthesis.

Table 1.1. Summary table of appraisal tools used in thematic synthesis

Appraisal tool	Description
Reading guide by Sandelowski & Barroso [79]	Comprises 14 separate domains: research problem, research purpose/questions, literature review, mindset toward the target phenomenon, method, sampling strategy/ techniques, sample, data collection techniques/sources, data management techniques, findings, discussion, validity, ethics and overall form.
Hawker's et al. [80] checklist	A validated scoring system that comprises of ten questions/ components each one given a quality score ranging from 4 (good) to 1 (very poor), which generates a maximum score of 4.
Typology for classifying findings in qualitative studies by Sandelowski & Barroso [79]	The typology is presented in the form of a "continuum of data transformation": i. no findings, ii. topical survey, iii. thematic survey, iv. thematic/conceptual description, and v. interpretive explanation.

Following the selection of appraisal tools, a decision on the method to synthesise the retrieved studies was made. There is an array of different methods to synthesise qualitative evidence [81, 82]. Of these, two were considered for answering the research question: critical interpretive synthesis [83] and thematic synthesis [84].

These two approaches have important differences that merit attention. Firstly, an important point of difference is the extent to which they problematise the literature. Whilst critical interpretive synthesis critiques the literature it reviews, thematic synthesis does not share the same approach. This is due to the former including studies in the synthesis process that use qualitative and quantitative methodologies. Secondly, they differ in the level of narrowness of the research question set for the review. In critical interpretive synthesis the research question is broad; the terminology used is quite flexible and created through an iterative process. On the other hand, thematic synthesis incorporates studies based on a very specific range of qualitative methods (i.e. interviews and focus groups) that were also formed by an equally specific range of philosophical assumptions. These differences are summarised in *Table 1.2* below.

Table 1.2. Comparison of thematic synthesis versus critical interpretive synthesis.

	Thematic Synthesis	Critical Interpretive Synthesis
<i>Epistemology</i>	Critical Realism: “knowledge of reality is mediated by our perceptions and beliefs”	Subjective Idealism: “there is no single shared reality independent of multiple alternative human constructions”
<i>The question designed to answer</i>	Children’s experiences of healthy eating [84]	Access to healthcare by vulnerable groups [83]
<i>Approach to quality assessment</i>	Criteria-based: 12 criteria used (5 related to reporting aims, context, rationale, methods and findings, 4 relating to reliability and validity, 3 relating to the appropriateness of methods for ensuring that findings were rooted in participants own perspectives).	Non-criteria-based: quality of research judged to extent to which it informs theory.
<i>Extend of iteration</i>	Some iteration at coding and synthesis stages (phase 2-3).	During the searching process (unclear through the rest of the review)
<i>Problematizing the literature</i>	No	Yes
<i>Going beyond the primary studies</i>	Transformation	Transformation
<i>Synthetic product</i>	Directly informs policy makers and practitioners	Requires further interpretation by policy makers and practitioners.
<i>Data (homogeneous or heterogeneous)</i>	Heterogeneous sample but limited in qualitative methodologies	Heterogeneous sample: data deriving from qualitative and quantitative studies

As the aim of the review was to synthesise only qualitative evidence on a very particular population, the thematic synthesis approach was a more appropriate one to best answer the research question and therefore critical interpretive synthesis was rejected. Thematic synthesis is an approach that combines elements from meta-ethnography and grounded theory and allows methodologically heterogeneous studies to be synthesised [81, 84]. It was developed out of a need to conduct reviews that addressed questions relating to intervention need, appropriateness and acceptability without compromising on key principles developed in systematic reviews. It shares characteristics from later adaptations of meta-ethnography in that analytical themes are comparable to third order interpretations and that the development of descriptive and analytical themes using coding invokes reciprocal translation. Alternatively, it shares with grounded theory the fact that the approach is inductive and themes are developed using a 'constant comparative' method [81]. It is philosophically underpinned by critical realism according to which the "knowledge of reality is mediated by our perceptions and beliefs" [81]. The end synthetic product has the added value of informing policy-makers and healthcare practice.

The analysis process consists of three steps:

1. Free line-by-line coding of the findings of the preliminary studies. The verbatim findings of each of the selected studies are entered into a database with the aid of the NVivo® analysis programme. The term 'findings' refers to all text written under the titles 'results' or 'findings' in the original papers. That is to say that row/in vivo data (participant quotes) are imported into the dataset. The developers of the method argue that this was a way of dealing with the fact that some studies were very descriptive and rather summarised what the participants said than actually explained them; these are the topical and thematic surveys according to Sandelowski's [79] typology of classifying qualitative findings. In this step these codes are developed either without hierarchical structure or in the form of a tree. At this step the translation of concepts from one study to another occurs. However, as Thomas describes, as the synthesist moves on and adds more studies, the codes will either be added to the existing ones or new ones may be developed as necessary. Normally, every sentence would have at least one code assigned to it and most would be categorised in more than one code. The final step in this stage is to examine all the text that had been given the codes in order to check for the consistency of interpretation and to see whether additional levels of coding are needed.
2. Development of 'descriptive' themes. In this step the free codes are organised into related areas in order to create the descriptive themes. In this stage the reviewer is looking for similarities and differences between the codes in order to start grouping them

in a more hierarchical tree structure. New codes may be created in order to capture the meaning of groups of the initial codes.

3. Development of 'analytical' themes. In this step the descriptive themes are organised into more abstract analytical themes in order to answer the research questions of the synthesis. This stage is similar to the third level of interpretation that meta-ethnography states; the effort to go beyond the original studies. It can be done independently and then at group level. Through a cyclical repeated process, analytical themes are created that will describe or explain all the initial descriptive themes.

The final sample for this thematic synthesis consisted of nine original papers reporting on eight studies for a total of 77 patients diagnosed with acute leukaemia [70-78]. Patient sample sizes varied from 4 to 21 patients; six studies (67%) originated from Europe. The majority of the papers (n=6) were published from 2001-2013. More than half of the papers adopted a grounded theory approach (56%). Other methods included hermeneutic phenomenology, content analysis, and ethnography. A summary of the characteristics of the articles reviewed is provided in *Table 1.3*.

The literature provided 287 free codes, which were organised in hierarchical order under a range of eleven descriptive themes; namely: initial reactions to diagnosis; life in hospital; losses; interpersonal relationships; emotional impact; coping; hope; support; information; personal values; and finding meaning. In the final synthesis stage the following four analytical themes emerged: the blow of diagnosis; a contracting world; buffers; and accommodating leukaemia. An organisational schematic of the deriving conceptual framework is presented in Figure 1.

Table 1.3. Summary of characteristics of the 9 articles included in the Thematic Synthesis [68]

Study, year; origin	Research design	Theoretical framework, method & analysis	n	Sampling	Demographic characteristics	Context	HC;T
Farsi et al. [72], 2012; Iran	Exploratory, longitudinal; 3 serial interviews: pre-transplant, 2-6 months post-transplant	GT by Corbin & Strauss	10	Convenience	Age Range: 18-48 yrs; 6 AML, 4 ALL, 70% married	Specialised BMT centre	35; CD
Koehler et al. [74], 2011; Germany	Exploratory, cross-sectional	GT & Content analysis; SSI	12	Consecutive	Age range: 21-76 yrs; 6 men, all AML	Haematological ward	27; ThS
Farsi et al. [71], 2010; Iran	Exploratory, longitudinal; 3 serial interviews: pre-transplant, 2 6 months post-transplant	Content analysis	10	Convenience	Age Range: 18-48 yrs; 6 AML, 4 ALL, 70% married	Specialised BMT centre	33; TS
Meenaghan & Dawling, [76], 2010; Ireland	Exploratory, cross-sectional	IPA by Heidegger; SSI, Van Manen's analysis	7	Purposive	Age Range: 60-79 yrs; 4 men	Haematological ward	29; ThS
Koenigsmann et al. [75], 2006; Germany	Exploratory, cross-sectional	GT & Content analysis; SSI	12	Consecutive	Age Range: 21-70 yrs; 6 AML, 6ALL, 5 male	Haematological ward	30; ThS
Friis et al. [73], 2003; Denmark	Exploratory, longitudinal; 2 serial interviews: after diagnosis, 2-5 months later.	Ethnography, SSI, domain analysis	21	Consecutive	57% > 50 yrs; all AML	University Hospital	35; TD
Berterö [77] 1998; Sweden	Exploratory, participant observation	GT, CCA	4	Theoretical	Age Range: 31-61 yrs; 3 AML, 1 CML	Haematological ward	36; CD
Persson et al. [78] 1995; Sweden	Exploratory, cross-sectional	Ricoeur's hermeneutic phenomenology	5	Consecutive	Age range: 60-77; 4 AL, 1 HML	Haematological ward	28; ThS
Bertero & Ek [70], 1993; Sweden	Exploratory, cross-sectional	GT, SSI	8	Theoretical	Age Range: 22-73 yrs; 4 AML, 3 ALL, 1 CML	County Hospital	33; CD

Abbreviations: BMT = Bone Marrow Transplant; GT = Grounded Theory; HC = Hawker's Checklist score; T = Typology; ThS = Thematic Survey; CD = Conceptual Description; TD = Thematic Description; TS = Topical Survey; CCA = constant comparative analysis, SSI = Semi-Structured Interviews, IPA = Interpretive Phenomenological Analysis; AML = Acute Myeloid Leukaemia; ALL = Acute Lymphoblastic Leukaemia; CML = Chronic Myeloid Leukaemia; yrs = years.

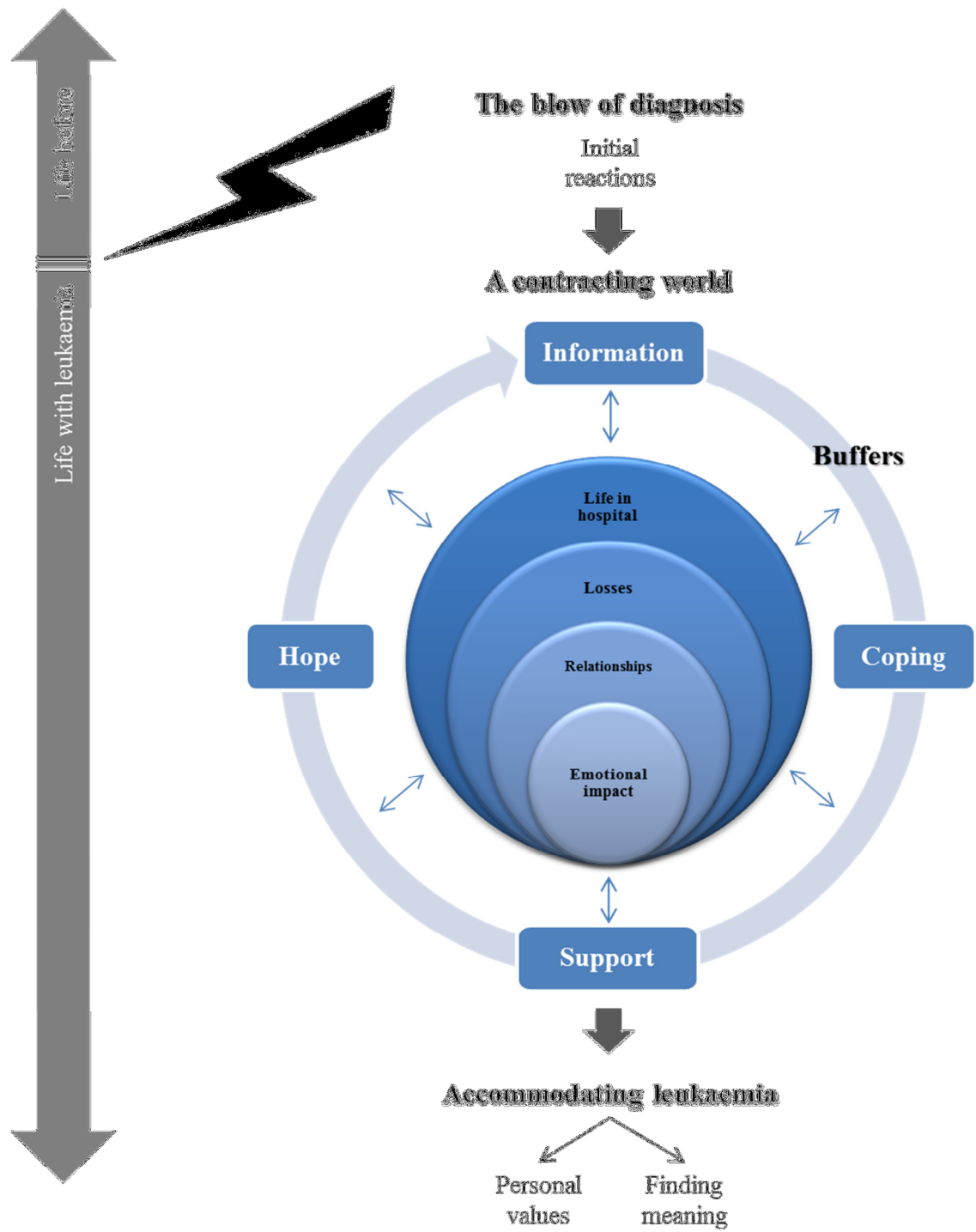


Figure 1. Qualitative thematic synthesis of the experience of acute leukaemia in adults

The blow of diagnosis

The diagnosis of acute leukaemia can shatter a person's life like a blow. The first encounter with the illness ignites a range of reactions, the type or the level of which does not appear to be influenced by gender [76]. The shock of diagnosis, feelings of disbelief ("it's not happening to me", "it's like a film") and fears of isolation ("the worst part of all is being in the room") were the most prevalent reactions [73-76]. The actual moment of learning the diagnosis was extensively described in the studies, focussing on the words that were used by participants and the evoked emotional response, often described as a numb sensation, uncertainty and shock [72, 73, 75, 76]. Moreover, patients were found to struggle with the diagnosis due to the difficulty in attributing a cause to their leukaemia, as usually there had been no sign of them being ill [74, 75, 77]. The way these patients perceive illness is that minor symptoms are caused by minor illnesses, whereas major symptoms mean serious illnesses [72, 75]:

"Prior to diagnosis, most participants did not pay any attention to the signs and symptoms of their illness. They chose rather to relate such to prior experiences or other diseases" [72] (p. 101).

Even the word 'leukaemia' appears to be difficult to grasp. Patients may learn and adopt the terminology of the illness in their vocabulary, without necessarily understanding it [75].

Treatment initiation follows shortly after the announcement of leukaemia [73, 75]. This lack of time and space to prepare has an impact on patients' initial efforts to understand their illness. The quick onset of the treatment is the main factor in facilitating understanding of the seriousness of their condition [72, 74, 75].

A contracting world

In confronting the new reality, patients find themselves living in a contracting world. They move from being people moving in their own social context to being hospitalised patients, and finally, patients with leukaemia [77]. In a short period of time, their world has shrunk to the confines of their hospital bed, a transition symbolised further by the change in their clothing [72, 76-78].

Moreover, patients with acute leukaemia have to spend a significant amount of time in hospital to receive intensive chemotherapy. Life in hospital is dominated by diagnostic procedures and treatment decisions, that is to say, rates regarding prognosis and effectiveness of the treatment [73, 75, 77]. Among the most prevalent procedures is bone marrow biopsy, often seen by patients as a violation of their integrity and a reminder of the threat of

leukaemia [75]. Dealing with the side effects of treatment, such as fever and fatigue, is another part of hospital life [71, 72, 75, 77, 78]. Interestingly, patients did not always understand the seriousness and relevance of these symptoms to their overall health status [75, 78]. The emotional impact of acute leukaemia becomes more evident at this stage. The diagnosis of leukaemia leaves no space for reflection; it is at this point that patients start to feel threatened and, in certain cases, helpless [75, 78]. They live in a world of uncertainty, doubts and fear of death [71, 72, 76, 77].

Due to the increased risk of infection during myelosuppressive treatment, patients face deliberate social isolation [71, 72, 76-78]. While they comprehend the reasons for this physical confinement, they fear further alienation from their social world [76, 77]. On several occasions, nurses' negative attitudes when performing tasks without actually spending quality time with them further increased their sense of isolation [77].

In their isolation rooms, patients also begin to realise their losses: the loss of personal control, loss of independence, loss of normality and the loss of their future. Everything is decided on their behalf and they are encouraged to follow clinicians' suggestions [74, 78]. Their daily routine is replaced by the hospital routine and then disrupted by the long-term effects of the treatment [72, 75]. Consequently, they see leukaemia as a threat to their ability for future planning and eventually as a threat to their life [75, 78].

The interpersonal relationships of patients with leukaemia can be illustrated as being organised in three circles; the first circle includes their family, the second includes their friends and the third level comprises the healthcare professionals [70, 76, 77]. Families, comprising the closest circle, face the greatest strain; friends are vital for socialising, while healthcare professionals may be patients' link with the outside world [77]. In all, the importance of interpersonal relationships was emphasised as *"an important source of strength which enables them to continue struggling, to go on living"* [70] (p. 1349).

Buffers

As a patient's world contracts, there are a number of factors serving as buffers, potentially absorbing the strains posed by acute leukaemia. The presence of support, information, coping, and hope all impact on how patients make sense of their experience.

Support

The importance of being supported in their new reality, either by healthcare professionals or their loved ones, was expressed in a number of accounts in the studies reviewed [70, 73, 76]. Patients recognise being respected as individuals and conversing with others as basic elements of support. Having faith and trust in clinicians and being respected in turn were important aspects of feeling supported and increased their sense of security [70, 75, 76]. Specifically, patients' sense of security was affected by waiting and visiting times as well as by communication with others [70, 76]. Conversely, lack of trust in healthcare professionals and not being respected as individuals by being put back in their 'patient-suits' were conceived as hindering support [70, 75, 77]. Furthermore, patients with acute leukaemia explained how support increased their level of autonomy. Autonomy was seen as an aspect of positive attitude with performance ability, self-esteem and dignity being its major components [70, 74, 78]. Even being able to manage seemingly trivial matters, like taking their own temperature, increased their feelings of independence [70].

Information

The type, time and level of impact of the information provided to patients with leukaemia comprised another buffer. Overall, patients with leukaemia were happy with the information they received [73, 75, 76]. Acknowledging the fact that not all patients want to be informed, providing accurate information to both patients and families was highly valued [70, 71, 73-75, 77]. From this set of studies, it was unclear whether information needs actually change over time [73]. Nevertheless, the impact of information was strongly stressed as a key element in enhancing QOL, in maintaining hope, reinforcing control and autonomy, facilitating acceptance and adaptation, and increasing trust in clinicians [70, 71, 73-76, 78].

Coping

In the studies under review, coping as a process was explored and a number of helpful and unhelpful coping strategies were reported. Factors that serve as barriers or facilitators for coping were also identified [72]. Taking action, which involves adaptation and acceptance, as well as consciously adopting a positive attitude, were the most common positive coping styles [71, 72, 76, 77]. Adopting a fighting spirit and taking charge of all possible resources; working through the difficulties; relying on faith and acknowledging their personal influence were also stressed [71, 72, 74, 75]. Patients with leukaemia may also use unhelpful coping styles, such as denial and avoidance; they can choose to keep a distance from the situation or even adopt a

more fatalistic attitude [71, 72, 74, 77, 78]. In fact, on several occasions, a patient could use contradictory coping styles [72, 75, 78].

Hope

Finally, patients perceived that hope helped them cope with their leukaemia [71-73, 75]. In fact, hope changed over time, with patients reporting increased hopes as their treatment progressed [72]. In all, patients' hopes were focussed on being able to control their leukaemia and thus look at their future prospects more positively [72, 73, 75].

Accommodating leukaemia

In order to build a renewed self, patients make sense of their experience through reprioritising their personal values and finding new meaning. The joy of being alive and in fact having a positive attitude towards life in general was vital for patients [70]. Life satisfaction, together with 'living for today', here and now, were values of paramount importance [71, 75]. Accordingly, leukaemia changed the perception of what accounts for a good QOL [70]. Patients reported finding happiness in small, trivial things and taking nothing for granted [70, 72]. Key elements that mediate QOL are the coping strategies patients implement, and information and support received from their clinicians [70]. This process indicated the beginning of reprioritising personal values [70, 72, 75, 76].

In the studies reviewed, it was apparent that having leukaemia leads patients to re-evaluate their lives [70-72]. Often patients questioned the meaning in life and the meaning of life [70, 75]. Their ability to socialise was an important resource for them; reflection and mindfulness enabled them to live their lives in full. As new meanings were created, patients' perceptions of themselves and of others may play an important role. They confront the issue of mortality by accepting the possibility of death [70, 72, 75, 76]. It is only then that they can experience closure and move on with their life [72].

This qualitative thematic synthesis provides a first systematic overview of the experience of acute leukaemia in adult patients and highlights its impact in their lives. Acute leukaemia is often perceived as a watershed moment in their lives, separating life before from life with the illness. The proposed conceptual model explains the path that patients follow in order to build a renewed self: dealing with the blow of diagnosis, living in a contracting world and accommodating their illness in their lives. However, the dearth of research in this population

remains, particularly when considering the variety of context within which the studies were conducted. Patients with acute leukaemia in the first stages of their treatment have different needs from those undergoing bone marrow transplantation; therefore, research targeting specific time-points in the cancer journey is needed.

1.3. The experience of acute leukaemia – the family caregiver perspective

Research on family caregivers of people with a chronic illness emerged in the decade of 1980; however, it is in the last fifteen years that it has increased substantially [15]. To date, the empirical investigation of caregiving has been mainly targeted on illnesses, such as stroke, Alzheimer's disease and cancer [85-88]. This wide focus on this growing population can be justified, not only by the increasing demands placed on individuals close to the ill person to undertake caregiving roles [89], but also by the rising expectations on the health system's part for these persons to act as 'co-caregivers' along with professional caregivers. Indeed, a number of factors, including nationwide increases in social welfare costs, complexity of the medical management of chronic illnesses, a shift of the balance of care from hospitals to community, and a shortage of healthcare providers, have led to the pressing need of greater and more prolonged active involvement of families in the daily support of the chronically ill person [9]. Current facts and figures reveal that in the UK alone, at least 6.5 million people provide care on an unpaid basis for a relative, friend or neighbour in need of support due to illness or frailty [90].

A carer has been described as a person 'who shares' the illness experience with the patient; a person who provides support and sustenance to the patient [7]. This person can be either a family member (often referred to as a family caregiver) or even a person considered to be family by the patient, including a friend or even a neighbour (more generally referred to as informal caregivers) [8]. For reasons similar to the ones stated above, the requirement for families to provide care to a family member diagnosed with cancer is also on the rise [91]. This section presents an overview of the caregiving experience in the context of cancer care, draws on a theoretical model on the cancer caregiving experience and finally, discusses existing evidence on caregivers of patients with acute leukaemia.

1.3.1. Caregiving in the cancer care context

In the context of cancer, research on family caregivers has increased over the last ten years, which is reflected in a number of systematic reviews being published on the topic [5, 15, 92-96]. Caring for a person diagnosed with cancer requires that carers balance a number of different tasks and roles, such as providing emotional and physical support, offering practical support on daily activities, managing financial issues and dealing with the healthcare system [5, 92]. It has been argued that these tasks and roles are related to the transitional state the patient experiences during the phase of treatment and do not necessarily follow a linear order in terms of how they develop [97]. Yet, there are certain areas that remain unclear, such as whether the type of cancer or the type of relationship has an influence on the assumed roles [5], or if and how these roles may change according to which phase of the illness trajectory the patient is in [98]. Equally, it can be proposed that caregiving roles or tasks may vary, not only according to patients' expressed or perceived needs, but also according to patients' capability for self-care [5].

Researchers have explored aspects, positive but predominantly negative, of the caregiving experience in a variety of different types of cancer, such as breast [99-101], colorectal [102, 103], prostate [104, 105], lung [106-114], ovarian [115-119], head and neck [120-123] and oesophageal cancer [124]. Family members assuming caregiving roles recognise this as a potentially rewarding experience, and indeed, findings from studies in cancer care reveal that family caregivers do stress the positive aspects of caregiving, such as the opportunity for strengthened interpersonal relationships [92] and the potential to evolve their everyday vulnerabilities into strengths as time passes [85]. Nevertheless, caregivers' practical and emotional involvement in the patients' cancer journeys can also have multiple impacts on a physical, psychological and social level [5, 125] that can be interpreted as stressors and create increased strain and burden. Researchers have described the caregiving burden as a "multidimensional bio-psychological reaction resulting from the imbalance of care demands relative to caregiver's personal time, social roles, physical and emotional states, financial resources and formal care resources given the other multiple roles they fulfil" (p. 3) [126]. Along these lines, two major aspects of caregiver burden have been identified; subjective and objective burden [86]. Subjective burden refers to various beliefs and personal attitudes regarding the caregiver's role [5]. Objective burden refers to the actual effort to meet the caregiving role, such as time spent on caregiving [5].

Recently, Fletcher et al. [15] highlighted the need for conceptualising the caregiving experience as a *whole* to guide future interventions in under-researched areas. This model comprises

three different components: the stress process, contextual factors and the cancer trajectory (Figure 2). A central part in the model is the 'stress process', which authors have expanded based on the classic stress models by Lazarus and Folkman [127, 128] and Pearlin et al. [129, 130]. Within this component lie five distinct elements: primary stressors, secondary stressors, cognitive appraisal, cognitive-behavioural responses, and health and well-being. This part of the model has been better supported in the literature [15]. Collective evidence published on a review of the literature indicated that the overall QOL of the caregivers varied between low, stable or high depending on the type of cancer and on whether the patient was receiving treatment or in-hospice care [131]. Yet, evidence on the symptom experience of caregivers of patients with cancer remains scarce, with the exception of depressive symptomatology [132]. Indeed, past research has shown trends towards significantly higher levels of depression and anxiety in caregivers of women with ovarian cancer as compared with norms ($p < 0.001$) [119]; similar results have been also reported for caregivers of patients with lung [110, 112] and colorectal [102] cancer. Among caregivers of patients with colorectal cancer, almost all carers reported suffering from psychological distress that was related to fear of the consequences of their emotional expression [125, 133].

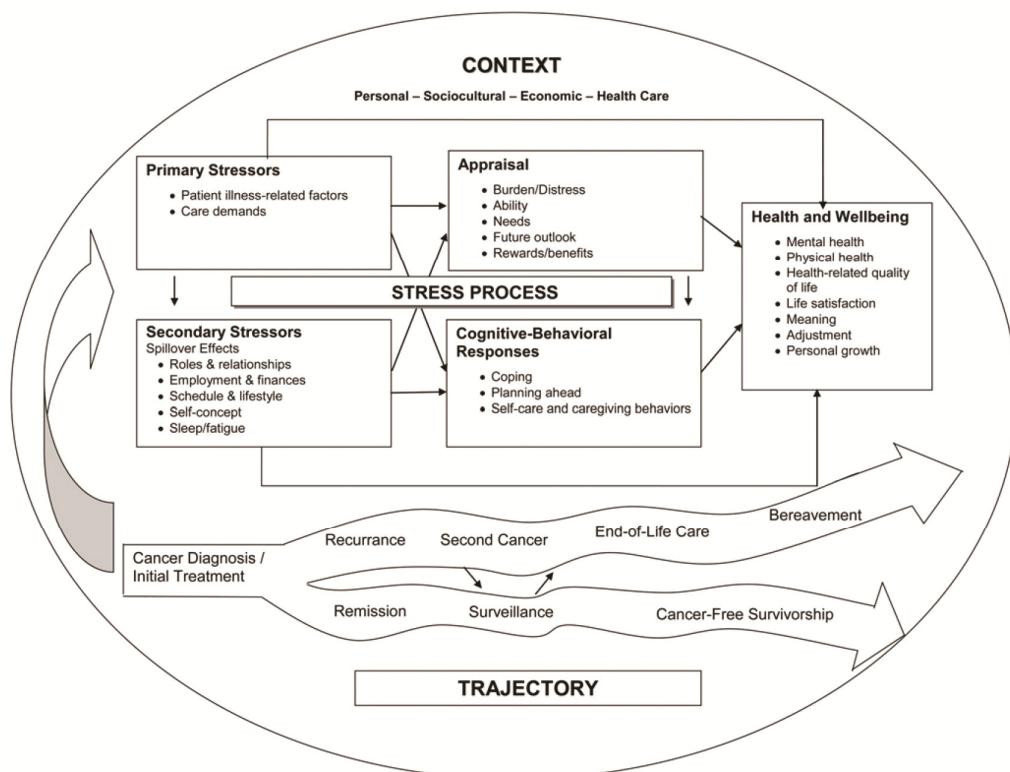


Figure 2. Conceptual model of the cancer family caregiving experience; Fletcher et al. [15] [reprinted with permission license]

The second part of the model concentrates on the 'contextual factors' that literature has addressed so far, namely age, gender, educational level, culture and socioeconomic status, personality type, social support and type of relationship, personal health, family dynamics and dyadic coping [5, 15, 92, 93, 126]. Yet, these different factors have not been looked upon equally within the current body of evidence. Other contextual aspects, such as health system services and prior health status, are yet to be explored [15]. Nevertheless, it has been proposed that younger caregivers seem to be more affected by disruptions in their schedules than older ones who viewed the experience as less negative over time [134, 135]. The age of the carer and health issues, depression, anger and anxiety of the patient may also adversely affect the caregiver's QOL [86, 102, 136], whereas higher levels of burden and distress may be associated with the caregiver's income and the patient's age [137]. In terms of influence of dyadic processes and family dynamics, stressors, including negotiating changes in occupational and family roles, dealing with interference with future life plans, and managing household and childcare responsibilities, may be prevalent within the relationship between patients and their caregiving partners [88].

The third component of the proposed model involves the 'cancer trajectory'. Within this aspect authors have suggested two different ways to conceptualise the term 'trajectory' [15]. One suggestion is to understand it in biological terms, that is to say, early versus advanced stage of the disease. A second option is to perceive the cancer trajectory in terms of important phases of the experience, or 'critical moments', such as diagnosis, end of treatment, remission or relapse [15, 98, 138]. Again, this part of the model is not well documented in the literature, due mainly to the cross-sectional nature of the majority of the published work [15], which has provided only a fragmented picture of the continuum of the caregiving experience. Yet, the need to understand the ways caregiving stressors, clinical outcomes and behavioural responses fluctuate during critical transitions in the shared patient-caregiver cancer journey is evident in an attempt to offer better and tailored supportive care.

1.3.2. Caregiving in the context of haematological malignancies/acute leukaemia

Despite a general trend towards the generation of increasingly more empirical evidence on the experiences of caregivers of adults with cancer, research specifically focussing on family

caregivers of patients with haematological malignancies is still in its infancy. Two main characteristics of the current available studies in this context can be reported here. First, there is a predominant interest in caregiver activities/experiences associated with the provision of care for patients undergoing BMT. Second, there is an almost exclusive trend towards the inclusion of mixed samples of caregivers of patients with various types of haematological malignancies. In fact, the number of studies exploring caregivers' experiences when caring for an adult with acute leukaemia remains next to zero, with existing evidence mainly relating to family caregivers of paediatric rather than adult patients [139].

The extent of research on caregivers of adult patients undergoing BMT can be reflected on two recently published systematic reviews that identified more than 20 relevant studies [140, 141]. In agreement with evidence from the wider cancer caregiving population [92, 94, 99, 101], although the caregiving experience can be rewarding and carers may experience personal growth and strengthened family bonds [140], aspects of QOL (physical, psychological, social, spiritual) may still be widely and adversely affected, while issues regarding the caregivers' roles as well as the availability of internal and external resources may also be apparent [141]. Caregivers may be subject to high levels of distress prior to transplantation, and in several cases higher than patients' own reported distress levels [140]. An increased risk of relationship maladjustment and dissatisfaction among female spouses whose husband was receiving BMT was also reported [86, 87]. Another factor that may have an impact on caregivers' distress is satisfaction with healthcare: the time prior to admission into hospital for BMT appears to be an equally significant emotional experience for both patients and their caregivers [142], and caregivers' perceived support from clinicians has been shown to impact on building a subsequent trusting relationship [143]. Interestingly, although the social aspects of QOL differ slightly from the caregivers of the general cancer population, caregivers of patients with haematological malignancies may also report a sense of isolation, especially those who have to deal with the issue of patient relocation to specialised centres that can obstruct their adjustment to living with the illness [141, 144].

Conversely, the current knowledge on the experience of caregivers of haematological patients in the non-BMT context remains significantly more limited. A search of the literature revealed only four published studies: two studies conducted during the active phase of chemotherapy treatment [145, 146]; one study concentrating on survivorship [147]; and one study in the end-of-life context [148]. Despite some interesting findings, this limited amount of widely diverse studies in terms of purposes, design and sample characteristics offers only glimpses to the overall caregiving experience, the picture of which remains fragmented. Persson et al. [146]

found that spouses of patients with acute leukaemia or lymphoma had increased feelings of loss of control. The authors identified three different styles of dealing with the situation: the couple acting as a unit, independently yet equally, and separately with the spouse in a secondary role. The couple's actions of regaining control were similar at diagnosis and changed later on as the treatment progressed according to the type of family and personal resources [146]. Provision of adequate and tailored information may also play a role to effective adjustment. In terms of information needs, caregivers of patients with haematological malignancies expressed a preference for primarily printed and face-to-face information, and to a smaller extent, internet-based information during the survivorship phase; yet, younger age and higher educational background was linked to a greater possibility to access and use electronic sources of information [147]. Moreover, while information needs changed throughout the cancer continuum, financial concerns and future outlook still represented the most important unmet needs as caregivers entered the survivorship period [145]. In a different context, McGrath [148] revealed a number of issues that were of importance for family members providing end-of-life care. Predominantly, the caregiver's role involved physical and emotional support provided both at home and during hospitalisation periods [148]. Caregivers valued their interpersonal relationship with their family member and expressed a need to be there at all times, which, due to the nature of the illness, was not always possible. Even so, resuming an advocate role for the patient, accommodating the different levels of information needs and facilitating communication with the clinical team were all reported as being important actions [148].

Strikingly, only one study was identified that was conducted with a sample (n=194) of family members who cared specifically for adult patients with leukaemia [10]. Findings of this cross-sectional study that included caregivers of patients in different phases of the illness trajectory revealed that increased burden, disruptiveness, positive adaptation, financial concerns and support were among those variables greatly impacting on the carers' QOL. Moreover, important aspects of carers' responsibilities that affected or promoted their well-being included expression of feelings and self-esteem, attendance to patient physical needs, security, confidence, household maintenance, family support, self-care, leisure activity and personal maintenance [10]. According to this study, recognising the educational and psychosocial needs of caregivers can be a crucial first step to enhance their QOL and well-being. However, as this was only one study relying on quantitative methods only and conducted within a certain sociocultural context that may have affected generalizability of findings, the need for more in-depth exploration of the experiences of this specific caregiving population is still pressing.

1.4. Appraisal of the current literature

In the previous sections, an overview of the literature on patients with acute leukaemia and their family carers was presented. This section attempts an overall appraisal of the available evidence with a specific focus on the current gaps and limitations.

Locating original articles from studies conducted in patients with acute leukaemia has proven very challenging. During the electronic searches, in the majority of the published material the population under investigation included mixed samples of patients with leukaemia (either acute or chronic), lymphoma and multiple myeloma. Moreover, in studies conducted in the context of BMT, samples also consisted of patients with breast cancer [149-151]. This is mainly because in the late '80s and '90s, BMT appeared as a promising new treatment for metastatic breast cancer [152]. Hence, the literature on patients with acute leukaemia remains sparse due possibly to the lower incidence rates compared to other types of cancer [20, 153]. In the interest of larger sample sizes and adequate power analysis, the majority of studies are conducted on patients with mixed haematological malignancies; therefore, patients with acute leukaemia consist of only a subgroup of the population under investigation. The reporting of results is usually presented as a whole group; in fact, there are only few cases where results from groups of patients with acute leukaemia were provided [30, 78, 146]. Furthermore, studies were conducted in a variety of different settings (local hospitals, university hospitals, specialised centres) and with patients with acute leukaemia in different stages in their cancer journey (diagnosis, relapse, or transplantation) receiving different treatments (induction, consolidation, or megatherapy). As a consequence, the interpretation of findings regarding specific subgroups, for instance patients after diagnosis, was not feasible.

Research on patients diagnosed with acute leukaemia consists mainly of quantitative observational studies with particular interest on health-related QOL, symptom experience, survival, psychological impact of acute leukaemia, and information needs [4, 24-31, 37, 53, 154, 155]. Of these outcomes, the literature for patients during the active phase of chemotherapy (induction) has focussed mainly on the impact on QOL [4, 28, 31]. Even though studies indicate that QOL is mostly affected during this period, it is not yet clear how patients with acute leukaemia make sense of their diagnosis, what their perceptions are and what coping strategies they implement. Findings from those studies employing qualitative methodologies and from the qualitative thematic synthesis of current evidence [68] provide more in-depth understanding of the experience of acute leukaemia as a whole. The resulting conceptual model explained the path that patients may follow in order to build a renewed self: dealing with the blow of diagnosis, living in a contracting world and accommodating their

illness in their lives [68]. Nevertheless, the issues regarding the context of the illness (the specific phase in the cancer journey) remain.

Regarding the methodological quality of the evidence provided, there are four issues worth mentioning. Firstly, as already mentioned, due to the nature of acute leukaemia, the sample sizes of the studies were mainly small. The samples were, in their entirety, convenient. What is more, none of the reviewed quantitative articles provided information on any power calculation analyses. Secondly, in the quantitative studies, the patient outcome measures that were used were not always suitable for the acute leukaemia population, who may face different challenges compared to other patients with solid cancers. Another problem was that measures were not always validated [42, 154, 156]. Thirdly, there was a lack of prospective studies. There were four longitudinal studies employing quantitative methods and no studies employing qualitative methodologies. The main issue for these studies was the high attrition rates. Fourthly, the quality of the qualitative studies is worth mentioning. For the studies included in the thematic synthesis, quality appraisal was performed with use of Hawker's checklist [80] and Sandelowski's [79] typology of classifying findings of qualitative studies. According to the typology, only four out of the nine included studies were classified as "conceptual" or "thematic" descriptions, while no study was classified as "interpretive explanation". Despite the fact that appraising qualitative work is a subjective task, the synthesis' findings may be compromised by the level of initial interpretation by the authors in the original studies.

In terms of the caregiver literature, a similar dearth of evidence on caregivers of patients with acute leukaemia was noted. As previously stated, only one study has focussed on the needs of family caregivers of patients with leukaemia (acute and chronic) [10]. The studies presented in the review reported findings from caregivers of a mixture of haematological conditions in a variety of contexts (diagnosis, transplantation, palliative care, and survivorship). Strikingly, whereas the experiences of carers during BMT is well documented [140, 141], no study was found exploring the experience of family members of patients with acute leukaemia during the initial stage of diagnosis and treatment or how they make sense of the illness itself. However, there is a pressing need to understand the entire context in which people experience and make sense of their illness, and particularly their interconnectedness with others. That is because a person's experiences are located and made sense of – among others, as mentioned before – in relation to their significant others. Unfortunately, due to the way the healthcare system focusses on patient-centred care, the family caregiver's role is not always fully recognised by healthcare professionals, resulting in a one-dimensional view of the patient

experience [9]. 'A change in one family member affects all family members' (p. 41) [157]. Hence, family caregivers are substantially distressed when a member has cancer, they do not always understand or respond supportively to the expressed thoughts about cancer of other family members, they try to find a balance between the impact of the cancer and the tension of the family, and in the meantime they try to maintain their core functions when one of them is a long-term survivor [158]. Therefore, caregivers should not be regarded solely as a patient's support system, but rather as individuals who may themselves be in need of additional family, social or other supportive services [142]. In order to reach such an accomplishment for the caregivers of patients with acute leukaemia it is crucial to see through their prism the experience of illness, and discover their perceptions and coping strategies.

1.5. Chapter summary

This chapter provided an overview of the literature regarding the overall experience of acute leukaemia from the perspectives of patients and family caregivers. Although several aspects, such as health-related QOL and psychosocial impact of illness, have been mainly addressed by the literature on patients and at a lesser extent on their family caregivers, there are still areas that merit further exploration. The qualitative thematic synthesis of the experience of acute leukaemia in adult patients also highlights the necessity for additional, in-depth qualitative exploration of the illness experience due to certain areas, such as the making-sense processes remaining unclear. Acute leukaemia may pose particular difficulties compared to other types of cancer due to its acute nature and the invasiveness of treatment it requires. For this reason, the following chapter focuses on the literature surrounding sense-making in the context of cancer.

CHAPTER 2 – Making sense

2.1. Introduction

“If there is meaning in life at all, then there must be meaning in suffering.”

V. E. Frankl [159]

Meaning is embedded in human nature [159-161]. Theorists support the idea that, when facing negative events that challenge their existing construction of the world, people will attempt to integrate their experiences (the ones of order and the ones of stress) in a new meaningful reality through a search for meaning [11-13, 162-168]. Certain prerequisites for the search for meaning have been proposed, such as individuality and specificity of the triggering event [160, 161]. One’s cultural background and previous experiences can also influence a person’s search for meaning [160]. Along these lines, the search for meaning has been linked to certain attributes: it is a process, is time-related, has individual significance and can have a linear order [161].

The literature on meaning has expanded substantially over the two last decades, providing useful insights on how people deal with stressful situations. To date, research on the concept of meaning and meaning-making, has focussed on a number of different contexts, including adverse events [161, 169-173], loss and bereavement [174-176], and health conditions, such as Chronic Obstructive Pulmonary Disease (COPD) [177], Human Immunodeficiency Virus Infection (HIV/AIDS) [178], spinal cord injury [179-181], chronic pain [182], multiple sclerosis [183-186], heart disease [187, 188], Parkinson’s disease [189], diabetes [190], and cancer [191-195]. Moreover, researchers have extensively investigated meaning in relation to psychosocial adjustment [193, 196-204], various aspects of coping [180, 181, 185, 188, 189, 200, 205-210] as well as other concepts such as posttraumatic growth [39, 151, 204, 211-213], self-identity [214] and subjective theories of illness [209, 215]. As Park [11] signifies, the positive relationship between creating meaning and positive adaptation is “an intriguing hypothesis” (p. 286). Nonetheless, evidence remains inconclusive as the relationship between meaning-making and psychological adjustment has been found to be positive in some studies [214, 216-218], but negative in others [196, 203, 219, 220]. In addition, meaning has been investigated in relation to religious coping, emotional processing coping and acceptance, again with mixed

results [205, 206]. Similarly, in studies where meaning-making was identified as part of coping efforts and where the relationship between these concepts was investigated, either positive [221] or negative [222] or no associations emerged [223], due possibly to diversity in the methods employed such as variation in the measures selected for the assessment.

Particularly in the context of cancer care, individuals facing cancer may use causal explanations (what caused cancer), selective incidence (why cancer happened particularly to them at that particular time of their life) and placement of responsibility (whose fault is the occurrence of cancer), but they will eventually decide to evaluate the significance of their cancer to their lives [12, 13].

The purpose of this Chapter is to present the evidence base regarding the concept of making sense in the wider context of cancer from the perspectives of patients and their family carers. The decision to draw upon the wider literature on cancer was made due to the lack of studies in the context of haematological malignancies. Prior to that, in order to clarify concepts, the integrated meaning-making model by Park and Folkman [11, 14] is briefly presented and definitions are provided. As discussed in section 1.2.2, the meaning of illness and the meaning of cancer treatment has been partially addressed in patients with haematological cancers. These studies are discussed again in relation to the wider literature on meaning. Similarly, the wider literature on how family caregivers create meaning of cancer is presented. Finally, an overall appraisal of the presented literature is provided to highlight gaps and limitations.

2.2 The meaning-making model

According to Baumeister [224] meaning is a “mental representation of relationships among things and events” (p. 15); therefore, there is a connecting force embedded in the concept of meaning. There are many different theories around the concept of meaning that draw upon life disruption [225, 226], rebuilding of autobiographical memories [227], cognition [228], and personal construct theory [229]. According to Park [11], all these different theorists converge in six basic principles regarding meaning: (a) people have a pre-set *global meaning*, that is to say, general orienting systems and worldviews according to which they interpret their experiences; (b) when a stressful event takes place, individuals appraise it and attach meaning to it, this is known as *situational meaning*; (c) the discrepancy between the appraised

(situational) meaning and the global meaning determines the level of distress; (d) this distress initiates a *meaning-making process*; (e) through this process people want to restore the previous balance; and (f) the final restoration (if occurred) impacts on adjustment to the stressful event [11]. The integrated meaning-making model by Park and Folkman [11, 14] is based on these six principles and can be seen as an expansion of the stress and coping model of Lazarus and Folkman [127, 230]. The current PhD study is underpinned by this model that integrates all these important tenets, provides operational definitions for the different components, and is frequently used in the context of illness [11, 231]. A brief presentation of the model (Figure 3) is provided in order to set the grounds for the evidence that will be presented in the two subsequent sections.

Global meaning refers to the ‘general orienting systems’ of individuals including systems of beliefs, assumptions, goals and feelings [14]. According to Janoff-Bulman [166, 232] people have fundamental principles or ‘schemas’ regarding how the world operates; these involve justice, control, coherence and predictability. Global goals involve representations of desired processes organised in hierarchies [11, 233]. Global meaning is constructed early in life and can be later modified depending on each person’s individual experiences [232, 233]. Despite the fact that global meaning is influential on the person’s emotional responses, the level of awareness of its existence is yet to be established [233].

Situational (appraised) meaning refers to the specific meaning a certain event or situation has for a person in a specific context [14]. Situational meaning starts when a stressful event occurs and involves different elements, including appraising, finding the discrepancy between appraised meaning and global meaning, initiation of a meaning-making process, meanings made, and one’s final adjustment [11, 14]. The initial *appraising* of the event has also been defined as ‘implicit meaning’ [234] and is constantly reassessed by individuals as conditions and contexts change [166, 168]. Closely related to this on-going reassessment are the discrepancies that emerge between global and appraised meaning that can create distress [11]. The process individuals undergo in order to decrease this discrepancy is referred to as *meaning-making process* or *making-sense process* [165]. Meaning-making can be conscious (i.e. deliberate) and subconscious (i.e. automatic) [14, 235]; can occur through assimilation or adjustment [11]; and can be cognitive or emotional [11]. Other theorists further conceptualise meaning as having two elements: ‘comprehensibility’ (i.e. make sense of an event) and ‘significance’ (i.e. what the value of the event is) [232, 236]. Viewed as the ‘end product’ of the whole process, the third core element of the model is the *meanings made* component that refers to the end product of the meaning-making process. Park [11] identified a number of

different meanings ascribed, namely the sense of having made sense; the sense of acceptance of the event; causal attributions, perceptions of growth; changed self; reappraised meaning of the event; changed global meaning; and changed meaning in life. Some theorists also connote that the meaning-making process eventually leads to better *adjustment* [11, 14, 237]. More precisely, for people to adjust to the new situation there must be some degree of meanings having been made. There are, however, opposing views according to which meaning-making is not necessary for a person to adjust to a stressful life event [238, 239]. The specific contexts within which these differing pathways take place, and the mechanisms and individual characteristics involved in each case, remain to be clarified by empirical research.

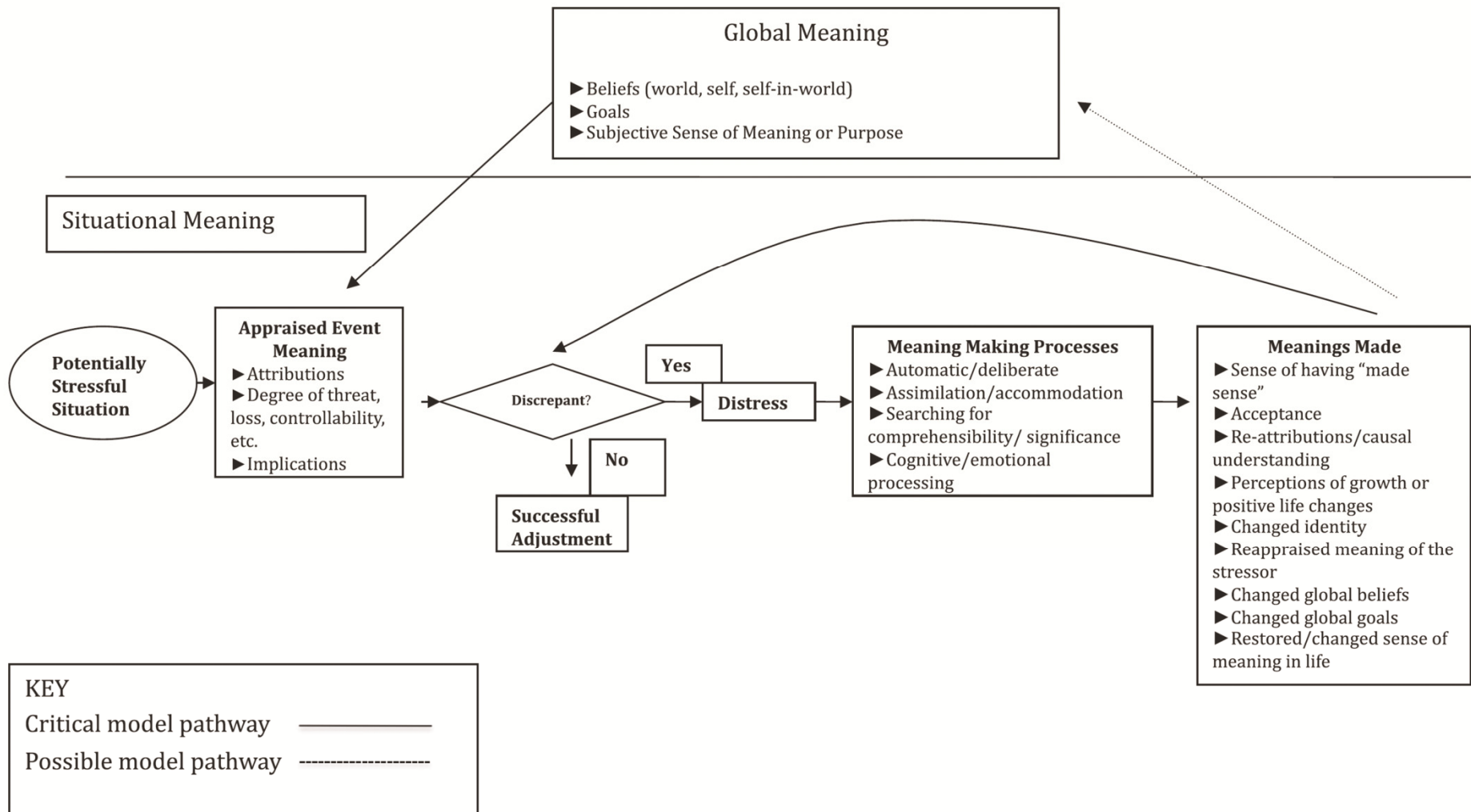


Figure 3. The meaning making model by Park & Folkman [11]

Indeed, despite the rising interest in the meaning-making model, Park [11] highlighted that research has not attempted to empirically test several aspects of the model in different settings and populations. Thus far, the majority of the body of knowledge derives from the context of illness (cancer), and bereavement, with limited research being carried out on other traumatic life experiences [11]. A further critique on the current body of evidence concerning the meaning-making model points at five areas that are worth mentioning. First, the majority of the research already conducted has not set out to test the model as a whole, rather it has focussed on a specific aspect of the model (e.g. the meaning-making process) [11]. To a certain extent, this strategy is justifiable by the universality of the model, which, in order to be adequately tested, would require significant resources, both human and material. However, arguably, deducting safe conclusions from the current data regarding the relationships among the components is not possible. Second, even though it has been proposed that meaning-making is a dynamic process which can develop, evolve and take different shapes over the course of time [14, 161], researchers have employed predominantly cross-sectional designs to elucidate the underlying processes, or the limited prospective studies ask participants to reflect on past periods, thus collecting data in a retrospective manner. The lack of such longitudinal data to further validate certain aspects of the model should be taken into consideration. A possible reason for this, according to Park [11], is that theorists have failed to propose a specific time frame according to which meaning-making occurs. Albeit theoretically feasible, it is however questionable whether it is realistic to *set* specific time-points where meaning-making could (or should) take place given the fundamental differences in the context of different chronic illnesses/adverse events and the subjectivity of a process that is greatly influenced by unique person characteristics. Third, the lack of consensus among researchers regarding the terminology used (e.g. meaning-making versus sense-making) places certain difficulties when bringing together evidence in reviews in order to examine the applicability of the model. Fourth, it has been proposed that the processes of meaning-making, either referring to situational or global, are to a certain extent occurring in the background of awareness, that is to say individuals may not necessarily be aware of these [232]. Finally, and most importantly according to Park [11], evidence remains limited due to the “problematic translation of rich theoretical conceptualisations to operational definitions” (p. 267), with the latter posing difficulties in selecting the appropriate measures to carry out research. In conclusion, despite the extensive research being published in the wider field of meaning, most elements of the model merit further testing. Taking into consideration this information, the next Section moves on to provide a review of the most recent research evidence in the context of cancer published over the last decade.

2.3 Making sense in the context of cancer – the patient perspective

A systematic review regarding meaning in the cancer context was published in 2004 summarising evidence under four main categories: global meaning, appraised meaning, search for meaning, and meaning as outcome [231]. In order to provide more up-to-date information on the advances of research during the past decade, this section updates this review by including evidence published from 2004 up to 2012. A systematic search strategy was devised and run in four electronic databases: Medline, Embase, Web of Science and CINAHL. Additional limits of English language and papers published in peer review journals were applied. In the interest of comparability with the previously published review, articles reporting on the development of meaning-making measures, or studies particularly examining adjustment processes such as growth or self-transcendence, but where no connections to other meaning-making aspects were made [11], were excluded from this review. The systematic search strategy can be found in Appendix 2.

The search yielded 45 relevant papers, reporting on 43 original studies. The majority of these studies employed a quantitative methodology (n=22), while seven papers reported results from intervention studies. Forty-four per cent of the studies were conducted in the USA and 30% were conducted in Europe (UK, Sweden, Germany, Netherlands, Denmark, and Greece). Most of the studies were in the context of active chemotherapy treatment (n=17); another ten studies reported findings from participants during survivorship. About half of the retrieved studies (n=20) were conducted with mixed cancer populations and approximately one-third focussed specifically on patients with breast cancer. However, a number of identified studies conducted among the wider haematological population dealt with some aspect of meaning of illness or meaning of cancer treatment [49-52]. The majority of the studies employed a cross-sectional observational design; six studies utilised a longitudinal design [203, 204, 240-245]. Six papers reported results from studies testing interventions, including psychotherapy sessions specifically designed to facilitate meaning-making-process, either in a one-to-one basis [246-251] or in the form of group meetings [252]. The qualitative studies employed a variety of different methodological approaches, such as hermeneutic phenomenology [253-256], grounded theory [257-260], and ethnography [261-263]. Summary tables of the identified quantitative (*Table 2.1*), qualitative (*Table 2.2*) and intervention (*Table 2.3*) studies are presented below. The findings of this review are grouped into three major clusters: (a) global meaning, including the sub-category of existential meaning/meaning in life; and (b) meaning of illness and (c) meaning-making process, both as part of the overall situational meaning. Due to the diversity of the sample the studies are presented in a narrative format.

Table 2.1. Summary of characteristics of the 21 studies (22 articles) identified employing observational quantitative methods.

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
Anagnostopoulos et al. 2010 [264]; Greece	To investigate the moderating and mediating role of global meaning and emotional expressivity (and coping) in the relationship between intrusive thoughts and psychological adjustment Women with breast Ca post-treatment completion	Cross-sectional Descriptive Correlational	n=153 Age: 58.4±10.1 (33-80) y; 67% Married; 56% No family history of Ca; 51% Stage 0 or I disease, 47% Stage II; 100% Surgery, 60% RT, 39% CT, 33% HT; Time since surgery: 5.2±4.7 y	Global meaning, but not emotional expressivity, had both direct and mediating effects on psychological adjustment. A strong sense of personal meaning and purpose in life, and an integrated understanding of self and life may lessen the impact of intrusive thoughts on psychological adjustment and mental health.	Illness-related meaning, personality traits, or social support were not included as moderating/mediating covariate. Cross-sectional design prevented from establishing directionality. Generalizability limited to women with early stage breast Ca, 5 y post-surgery.
Bauer-Wu and Farran 2005 [265]; USA	To compare personal meaning in life, spirituality, perceived stress and psychological distress in women with breast cancer to an unmatched sample of healthy women, and to examine the relationships among these variables Women survivors (>5 y post-diagnosis) of breast Ca	Cross-sectional Comparative Descriptive	n=39 (Survivors) – 39 (Healthy women) <u>Survivors</u> Age: 49.4 y; 92% Caucasian; 67% Married/partnered; Education: 15.4 y <u>Healthy women</u> Age: 42.6 y; 90% Caucasian; 72% Married/partnered; Education: 18.7 y	Survivors without children (n=7) scored higher on all measures (indicating poorer outcomes) when compared to survivors with children and healthy women with and without children. Moderate correlations (r=0.39-0.43) were found between personal meaning and spirituality, perceived stress and psychological distress.	No matching between the two groups – groups significantly different in terms of demographic characteristics. Small sample size with respect to analyses according to parity status.
Bower et al. 2005 [240]; USA	To evaluate prevalence and stability of perceptions of positive meaning and vulnerability, to identify their antecedents, and to determine their impact on long-term adjustment Women survivors (1-5 y and 5-10 y post-diagnosis) of breast Ca	Prospective Longitudinal (T1 within 1-5 y, T2 within 5-10 y post-diagnosis) Observational	n=763 Age: 55.6 (30-87) y; 84% Caucasian; 73% Married/partnered; 42% CT, 60% HT; Time since diagnosis at T1: 3.4 (1-5) y	The majority of women (>60%) reported positive changes in outlook and priorities at both T1 and T2. A substantial number of women (23%->40%) reported at least a fair change in their feelings of vulnerability. In adjusted analyses, positive meaning was a significant predictor of positive affect, whereas vulnerability significantly predicted negative affect.	Assessment of meaning and vulnerability at 1-5 y does not accurately capture changes in these dynamic processes. Perceived impact and intentional engagement with stressors were not included as predictors. No generalizability in ethnically/culturally diverse groups.

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
Büssing and Fischer 2009 [266]; Germany	To investigate meaning of illness and to analyse inter-correlations between positive and negative meaning, health-related variables and adaptive coping strategies Survivors of Ca at a conference of breast Ca support groups	Cross-sectional Correlational Descriptive	n=387 Age: 59.7±7.3 y; 72% Married/partnered; 81% Breast Ca, 4% Colorectal Ca, 3% Ovarian Ca, 12% Other; 21% Recurrence; Time since diagnosis: 10.9±6.4 m	Most participants regarded their illness as a challenge (52%), value (38%) or irreparable loss (35%). Negative interpretations (interruption/ loss and enemy/threat) were inversely correlated with mental health-related QOL and life satisfaction. Positive interpretations (challenge/value) were correlated with adaptive coping strategies.	Cross-sectional design prevented from establishing directionality. Recruitment biased towards patients with breast Ca. No regression analyses to adjust for the effects of predictors tested.
Down-Wamboldt et al. 2006 [267]; USA	To explore the relationship between meaning of illness, perceived social support, coping strategies and QOL, and to investigate between-group differences in these variables Patients with lung Ca (NSCLC) (within 6 m post-diagnosis) and their family members	Cross-sectional Correlational Comparative	n=85 pairs Patients: Age: 66.3±8.7 y; 58% Males; 98% Caucasian; 73% Married; 100% NSCLC; 62% Stage I, 19% Stage II disease, 6% Stage IIIA disease	For patients, regression results indicated meaning of illness perceived as manageable as the strongest predictor (31% of variance) of QOL.	Cross-sectional design prevented from establishing directionality. Sampling biased towards inclusion of patients with NSCLC. Fear of recurrence was not examined as potential covariate. Regression models were not adjusted for demographic/ clinical covariates.
Fife 2005 [268]; USA	To explore factors that influence the meaning constructed in response to a crisis, and to investigate the impact of meaning on emotional distress and mental health Newly diagnosed patients with Ca receiving treatment Patients with HIV/AIDS receiving treatment	Cross-sectional Comparative Descriptive	n=76 (Patients with Ca) – 130 (Patients with HIV/AIDS) Patients with Ca: Age: 52 (21-82) y; 59% Females; 79% Married/partnered; 19% Required assistance with daily living; Breast Ca, Lung Ca, Leukaemia	The meaning constructed in response to a crisis can be operationalized and its role evaluated as a dimension of the adaptation process. Constructed meaning affects self-perception, which subsequently affects adaptation. The pattern of effects does not differ by illness type.	Additional stressful life events were not included as covariates. Sampling biased towards inclusion of male patients with HIV/AIDS. Cross-sectional design prevented from establishing directionality.
Fleer et al. 2006[269]; Denmark	To examine meaning and its relationships with socio-demographic, cancer-related variables and life events; and	Cross-sectional Descriptive Observational	n=354 Age: 44 (18-79) y; 85% Married/partnered; 15% Chronic disease; 65%	Survivors of testicular Ca experienced their lives as meaningful. No associations with or educational level emerged, but partnered patients scored higher for meaning.	Cross-sectional design prevented from establishing directionality. Focus on the objective disease characteristics rather than the

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
	examine the contribution of meaning in the prediction of psychosocial well-being and cancer-related distress. Men survivors (>3 m post-treatment) of testicular Ca.		Combined surgery plus RT/CT; 35% Surgery; Time since treatment: 10 y (3 m-24 y)	Patients who had experienced more negative life events scored lower for meaning. Meaning is the most important predictor for psychosocial well-being, but its relationship with cancer-related distress is weak.	more subjective such as psychological and/or physical after-effects. Sampling bias possible – only 50% of the patients invited took part in the study.
Jim and Andersen 2007 [241]; USA	To test meaning in life as a mediator of the relationship between impaired physical/social functioning and distress <u>Study I:</u> Survivors of Ca <u>Study II:</u> Women survivors (>2 y post-diagnosis) of breast Ca	<u>Study I:</u> Cross-sectional Descriptive <u>Study II:</u> Secondary non-prospective analysis of a longitudinal trial Observational	<i>n</i> =420 (I); 167 (II) <u>Study I:</u> Age: 50.5±10.7 y; 79% Female; 93% Caucasian; 66% Married; 33% Breast Ca, 25% Gynaecological Ca, 12% Colorectal Ca, 6% Prostate Ca; Time since diagnosis: 4.9±5.0 y <u>Study II:</u> Age: 51.3±10.6 y; 92% Caucasian; 68% Married; Time since diagnosis: 1.9±0.4 y	<u>Study I:</u> Controlling for physical or social functioning, meaning in life accounted for 39% and 21% of variance in distress, respectively, reducing the variance in distress explained by the former variables. Partial mediation occurred. <u>Study II:</u> The significant indirect effects of functioning impairments on distress through meaning were replicated even with a 1-year interval. Full mediation of the relationship between social functioning and distress was found; partial mediation between physical functioning and distress also emerged.	Measurements in the longitudinal study took place at different time-points for different variables. Longitudinal study part of clinical trial – participants might not accurately reflect characteristics of the general population of survivors of breast Ca. No generalizability in ethnically/culturally diverse groups.
Jim et al. 2006 [242]; USA	To examine the relationship between coping with diagnosis and self-reported meaning in life 2 years later Women survivors (>2 y post diagnosis) of breast Ca	Secondary non-prospective analysis of a longitudinal trial Observational	<i>n</i> =167 Age: 51±10 y; 92% Caucasian; 90% Stage II disease, 10% Stage III disease; 54% RT/CT, 30% CT only	Adjusting for depression and cancer-related stress at baseline, coping at diagnosis predicted significant variance 2 years later for each dimension of meaning in life (5%-43% across models), with all models significant.	No measure of meaning in life at diagnosis, or coping strategies at 2 years. No measure of one's personality characteristics. Longitudinal study part of clinical trial – participants might not accurately reflect characteristics of the general population of survivors of breast Ca.
Kernan and Lepore 2009 [203]; USA	To characterise the frequency and stability of searching for and making meaning over time, and to	Longitudinal (T0 within 3 m; T1 within	<i>n</i> =72 Age: 52.7±11.2 y; 96% Caucasian; 78% Married;	Four search for meaning patterns emerged: continuous (44%), exiguous (28%), delayed (15%) and resolved (13%).	Single-item measures of searching and making meaning were used. No generalizability in

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
	describe whether different patterns of making meaning have different relations to negative affect over time Women with breast Ca within 4 m post-diagnosis	11 m; T2 within 18 m post-diagnosis) Observational Part of a larger study	54% Stage I disease, 35% Stage II disease, 7% Stage III disease; 44% CT, 33% RT, 14% RT/CT, 9% Other; Time since diagnosis: 96.4±45.4 d	Just over half of the patients reported having made meaning at early and late time-points. Controlling for baseline characteristics, a higher level of searching for meaning was associated with a higher level of negative affect, especially those women engaging in an on-going, unresolved search for meaning.	ethnically/culturally diverse groups. Possible reporting bias since 10 patients were excluded from analyses due to attrition.
Lethborg et al. 2007 [202]; Australia	To explore the associations of suffering and coping with psychological distress and global meaning Patients with Ca receiving active treatment or supportive care at an outpatient oncology service	Cross-sectional Descriptive Observational	n=100 Age: 57 (19-87) y; 59% Females; 53% Married; 35% Breast Ca, 30% Haematological Ca, 9% Upper GI Ca, 8% Lung Ca; 45% Stage IV disease; 63% Chemotherapy; Time since diagnosis: 32% <1 y; 34% <5 y; Length of disease: 31 (4-312) m	Physical and existential distress were positively associated with psychological distress. High social support and personal meaning were linked to lower levels of psychological distress. Social support was the strongest correlate of global meaning; high levels of existential distress were related to lower levels of global meaning.	Cross-sectional design prevented from establishing directionality. Recruitment biased towards patients with breast and haematological malignancies.
Park et al. 2008a [270]; USA	To examine psychosocial factors and coping behaviour associated with both positive and negative health behaviour changes Survivors of Ca	Cross-sectional Descriptive Survey	n=250 Age: 45.2 y; 89% Caucasian; 73% Married/partnered; 46% Breast Ca, 12% Prostate Ca, 6% Colorectal Ca, 5% Gynaecological Ca; 53% Surgery only, 35% Surgery plus RT/CT; Time since primary treatment: 1.6 y	Social support, sense of control over illness course, meaning in life and approach coping were associated with positive health behaviour changes. Lack of meaning in life and avoidance coping was related to negative health behaviour changes.	Sampling bias possible – only 42% of the patients invited took part in the study. Cross-sectional nature of the study precludes causal inferences. Recruitment biased towards inclusion of patients with breast Ca.
Park et al. 2008b [204]; USA	To test a model of meaning and adjustment to Ca that distinguishes between the <i>process</i> of meaning making and the <i>products</i> of that	Prospective, repeated measures (two time-	n=(250) 172 Age: 45.2 y; 69% Females; 88% Caucasian; 73% Married/partnered; 47%	Meaning-making efforts are related to better adjustment through the successful creation of adaptive meanings made from the cancer experience.	Measurement of some meaning-making constructs might have been insufficient. Sampling bias possible – only 42%

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
	process. Survivors (within 2.5 y post-diagnosis) of Ca under 50 years of age	points 1 y apart) Observational	Breast Ca, 12% Prostate Ca, 6% Colorectal Ca; Time since treatment: 23.4±14.5 (12-40) m		of the patients invited took part in the study. Possible bias towards inclusion of patients with breast Ca.
Ponto et al. 2010 [271]; USA	To analyse demographic, clinical and meaning-related predictors of adjustment and growth Women with recurrent ovarian Ca (along with their spouses or partners)	Cross-sectional Observational Descriptive	n=60 Age: 59±8.9 (23-79) y; 97% Caucasian; 53% Two or more recurrences; 53% Current treatment (90% CT); Time since diagnosis: 65.4±46 (12-209) m; Time since first recurrence: 36.6±36.9 (0-176) m; Years in relationship: 31.6±12.9 (<1-56) y	A regression model of five predictors (younger age, fewer years in the relationship, poorer performance status, greater symptom distress, and more negative meaning) accounted for 64% of the variance in adjustment to Ca. None of the variables was associated with post-traumatic growth.	Small sample size affected power of the study. Cross-sectional design prevented from establishing directionality. No generalizability to non-Caucasian racial/ethnic and non-partnered groups of patients.
Sarna et al. 2005 [272]; USA	To describe QOL and examine relationships of demographic, clinical, health status and meaning of illness characteristics to QOL Women with lung Ca (6 m-<5 y post-diagnosis) at multiple recruitment sites	Cross-sectional Exploratory Correlational	n=217 Age: 65±12 (33-89) y; 85% Caucasian; 48% Married; 100% NSCLC; 24% Currently employed; 67% At least one comorbid condition; 74% Former smoker, 13% Current smoker	Most commonly, disruptions in psychological and social aspects of QOL were reported. 63% of women reported positive meanings of illness (53% reported illness as a challenge). Depressed mood, negative meaning and younger age explained 37% of variance in global QOL.	No generalizability to non-Caucasian racial/ethnic and patients with advanced disease. Cross-sectional design prevented from establishing directionality.
Schoen and Nicholas 2005 [273]; USA	To examine the relationships among health-related quality of life, coping and existential meaning Women with breast Ca at one cancer treatment centre	Cross-sectional Descriptive Survey	n=248 Age: 61±10.6 (30-80) y; 91% Caucasian; 75% Married; 39% Family history of breast Ca; 46% Stage I disease, 37.5% Stage II disease; Time since diagnosis: 3.2±1.6 y	Higher levels of quality of life were moderately correlated (r=0.45) with higher levels of quality of life. Regression analysis indicated that existential meaning and coping each contributed significantly (20% and 14%, respectively) to the variance in quality of life.	Sampling bias possible – only 37% of the patients invited took part in the study. No adjustment for sociodemographics in regression analyses models.

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
Sherman and Simonton 2012 [243]; USA	To explore associations between personal meaning and emotional distress, quality of relationships, perceived coping efficacy, and physical health Patients with haematological Ca receiving care in a stem cell transplant centre	Cross-sectional Descriptive Observational	n=104 Age: 57±9.8 y; 62.5% Males; 78% Married; 95% Caucasian; 82% Multiple myeloma, 15% Other haematological Ca, 3% Solid tumour; 63% Prior transplant; Time since diagnosis: Median 25 (1-182) m	Weak to moderate correlations between personal meaning and emotional distress ($r=-0.42$), relationship cohesion ($r=0.29$) and coping efficacy ($r=0.26$). No association with physical health. In adjusted regression analyses, personal meaning significantly accounted for 9%, 5% and 5% in the variance of distress, relationship cohesion and coping efficacy, respectively.	Cross-sectional nature of the study precludes causal inferences. No measures of depression or optimism. Mixed patient sample at different points post-diagnosis. Bias towards inclusion of patients with multiple myeloma. Also, 3 patients had solid tumours.
Sherman et al. 2010 [192]; USA	To examine the predictive ability of global meaning and illness-specific meaning of emotional adjustment, QOL and disease-related concerns Women with breast Ca (≥4 m post-diagnosis)	Repeated-measures (two time-points 4 m apart) Observational Correlational	n=73 Age: 58.4±10.8 y; 81% Caucasian; 74% Married; 100% Surgery, 38% RT, 48% CT, 59% HT; Time since diagnosis: 53.3±64.8 m	Adjusting for sociodemographics and baseline scores on dependent variables, global meaning significantly predicted BC-related concerns, but not QOL or emotional adjustment. Adjusting for sociodemographics and baseline scores on dependent variables, neither benefit seeking nor sense seeking nor their interactions with global meaning were related to any of the dependent variables.	Global meaning operationalized as generalised perceptions of life purpose and commitment only. Small sample size affected statistical power. No generalizability in ethnically/culturally diverse groups.
Simonelli et al. 2008 [274]; USA	To test meaning in life as a mediator in the relationship between physical symptoms and depressive symptoms Women survivors (2-10 y post-treatment) of gynaecological Ca returning for follow-up at one outpatient clinic	Cross-sectional Descriptive Observational	n=260 Age: 56±12 (23-83) y; 95% Caucasian; 70% Married/partnered; 51% Endometrial Ca, 27% Ovarian Ca, 18% Cervical Ca, 4% Vulvar Ca; 60% Stage I Ca; 96% Surgery, 43% CT, 20% RT; Survivorship: 4.2±2.0 y	The indirect effect of from physical sequelae to depression through meaning in life was a significant ($z=3.92$; $p<0.001$): survivors with more physical symptoms also reported lower levels of meaning in life, which was associated with greater depressive symptomatology.	Cross-sectional design prevented from establishing directionality. No generalizability to non-Caucasian racial/ethnic groups of patients.
Thompson 2007 [275]; USA	To determine relationships among cancer-related fatigue and meaning in life; overall symptom distress	Cross-sectional Descriptive	n=34 Age: 51±8.4 (36-70) y; 94% Caucasian; 82% Married;	One moderate negative correlation ($r=-0.42$) was found between fatigue (sensory subscale) and meaning (choice or	Small sample size may have affected power of the study. No generalizability to non-working,

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Main findings	Main limitations
	and meaning in life; fatigue and performance; overall symptom distress and performance Women survivors (within 16 m post-treatment) of breast cancer	Observational	38% Stage I disease, 38% Stage II disease; 56% Combination of surgery and RT/CT; 50% ≤6 m since last treatment	responsibleness dimension). Moderate to strong correlations were found for all other relationships tested.	non-Caucasian, younger women. Sampling bias possible – limited percentage (not specifically reported) of the patients invited took part in the study.
Vehling et al. 2011 [244]; Vehling et al. 2012 [245]; Germany	To examine global meaning, death acceptance and goal seeking as predictors of depression, anxiety and demoralisation To examine Ca stage, palliative treatment intent and physical problems as predictors of global meaning, existential distress (demoralisation) and depression Patients with Ca at one in-patient and one out-patient centre	Repeated-measures (two time-points) Observational Correlational	n=270 Age: 57±14 (18-88) y; 53% Males; 74% Married/partnered; 28% Haematological Ca, 19% Breast Ca, 17% Urologic Ca, 11% GI Ca; 57.4% Advanced Ca; 35% Palliative treatment; 36% Remission, 18% Recurrence, 19% Metastases; Time since diagnosis: 18.4±9.7 (3-384) m	Adjusting for age, gender and number of physical problems, higher global meaning significantly predicted lower depression and demoralisation. Death acceptance was a significant predictor of lower anxiety levels. Goal-seeking significantly predicted higher anxiety, depression and demoralisation levels. Adjusting for age, gender and partnership status, physical problems predicted higher demoralisation and depression at T2, but not global meaning (T1). Palliative treatment intent was a significant predictor of only higher depression at T2.	Sampling bias possible – only 41% of the patients invited took part in the study. Regression models of demoralisation and depression at T2 were not adjusted for T1 scores. Short time interval between the two assessment points. Not all patients aware of the palliative intent of their treatment.
Notes: Ca – Cancer; y – Years; m – Months; d – Days; CT – Chemotherapy; RT – Radiotherapy; HT – Hormonal therapy; QOL – Quality of Life; NSCLC – Non-small cell lung cancer.					

Table 2.2. Summary of characteristics of the 7 studies testing a meaning intervention

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Study conditions	Main findings	Main limitations
Breitbart et al. 2012 [246]; USA	To test the effects of the IMCP on spiritual well-being, QOL, anxiety, depression, symptom burden, hopelessness, and symptom-related distress compared to TM Outpatients with advanced Ca (stage III or IV)	Pilot RCT One baseline and two post-intervention assessments (immediately after intervention and at 2 m)	n=120 (64 IG – 56 CG) Age: 54.4±11.6 (25-82) y; 60.5% Females; 82% Caucasian; 48% Married; 26% Breast Ca, 16% Colon Ca, 9% Pancreatic Ca, 8% Ovarian Ca, 3% Lung Ca	<u>Intervention:</u> Seven-week (7 1-hour sessions) manualised and individualised intervention to assist patients in sustaining or enhancing a sense of meaning, peace and purpose in their lives. <u>Control:</u> Seven 1-hour sessions of massage therapy adapted from Swedish massage for frail patients.	Compared to CG, at post-treatment, significant improvements were found in the IG for spiritual well-being, QOL, symptom burden and distress, but not for anxiety, depression or hopelessness. No differences were found at the 2-m follow-up assessment.	Increased refusal rates and difficult recruitment responsible for low response rates. Sample size smaller than required; low statistical power. Attrition bias possible. Lack of usual care CG.
Breitbart et al. 2010 [252]; USA	To examine the impact of MCGP on spiritual well-being, meaning and psychological distress compared to standardised support group Outpatients with advanced Ca (stage III or IV)	Pilot RCT One baseline and two post-intervention assessments (immediately after intervention and at 2 m)	n=90 (49 IG – 41 CG) Age: 60±11.8 (21-84) y; 51% Females; 80% Caucasian; 19% Prostate; 16% Breast Ca, 13% Colorectal Ca, 13% Lung Ca; 63% Stage IV disease No between-groups differences at baseline	<u>Intervention:</u> Manualised 8-week group therapy (n=8-10 participants) to help patients sustain or enhance a sense of meaning, peace and purpose in their lives utilising didactics, discussion and experiential exercises. <u>Control:</u> 8-week 90-mins supportive psychotherapy intervention sessions focussed on discussion of issues themes that emerge for patients coping with Ca.	Compared to CG, at post-intervention, significant improvements were found in the IG for spiritual well-being and sense of meaning. No significant between-group differences were found psychological functioning; nevertheless, patients in the IG showed improvements in hopelessness, desire for death and anxiety at post-treatment, but especially at the 2-m follow-up.	Attrition bias possible, especially at 2-m follow-up. Challenging attendance of group therapy might have affected retention. Lack of usual care CG. Ceiling effects possible due to participation not contingent on specific level of distress.
Creswell et al. 2007 [247]; USA	To examine how expressive writing about emotions or benefits produces self-affirmation, cognitive processing and	Pseudo-experimental Secondary analysis One group, three intervention	n=60 Age: 49.5 (21-76) y; 93% Caucasian; 100% Stage I or II disease	<u>Intervention:</u> Essay writing (4 essays) during a 3-week period, where patients were asked to write continuously for 20 mins in an attempt to	Self-affirmation writing was associated with fewer physical symptoms at the 3-m follow-up. Self-affirmation fully mediated	Small sample size. Ambiguous strategy to construct and analyse mediators. Analyses did not account

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Study conditions	Main findings	Main limitations
	discovery of meaning, and how these processes affect health status Women with breast Ca (within 20 weeks post-treatment)	conditions One baseline and two post-intervention assessments (at 1 and 3 m)		achieve emotional expression, benefit-finding or fact-writing control with regard to their experience of breast Ca	the effects of the emotional expression and benefit-finding conditions on reduced physical symptoms. Cognitive processing and discovery of meaning writing were not associated with any physical health outcomes.	for baseline effects of health status/physical symptoms.
Henry et al. 2010 [248]; Canada	To examine the acceptability and usefulness of the MMi intervention, and to estimate parameters required to design a full-scale trial compared to usual care Newly diagnosed women with advanced ovarian Ca	Pilot RCT One baseline and two post-intervention (at 1 and 3 m) assessments	n=24 (12 IG – 12 CG) Age: 55±9.7 y 75% Married 79% Stage III disease, 21% Stage IV disease 100% Surgery plus CT Time since diagnosis: 45 d No between-groups differences at baseline, except CG had previously received counselling more frequently than IG	<u>Intervention:</u> Usual care plus MMi. MMi consisted of 1-4 intervention sessions of 30-90 mins each with a therapist who promoted self-exploration of impact and meaning of cancer diagnosis, past significant life events, and life priority and goal changes. <u>Control:</u> Usual care only (waiting list for MMi).	Compared to CG, patients in the IG had a better sense of meaning in life at 1 and 3 months post-intervention, with medium effect sizes (Cohen's $d=0.42$ and 0.41 , respectively). No significant effects on psychological distress or self-efficacy were found. Two patients in the IG dropped-out prematurely. Patients who completed the trial found the MMi useful and acceptable.	Lack of an attention CG to determine the effect of simply spending time with the interviewer. Variable intervention format might have affected effectiveness. Patients IG also received external counselling after the intervention. Performance bias possible.
Lee et al. 2006a [250]; Canada	To develop an intervention (MMi) that uniquely addresses the existential impact of Ca through meaning-making coping strategies, and to explore the MMi's impact on psychological adjustment. Patients with breast or colorectal Ca at different disease phases receiving	Prospective, pseudo-experimental, one-group One baseline and one-post intervention assessment (within 24 h after last session)	n=18 Age: 57±11.7 (38-76) y; 72% Females; 72% Married; 56% Breast Ca; 83% Diagnosed within past 3 m; 83% Stage I or II disease	<u>Intervention:</u> Up to eight individualised sessions in the patient's home or clinic that promoted self-exploration of impact and meaning of cancer diagnosis, past significant life events, and life priority and goal changes.	The final format of the MMi consisted of up to four two-hour sessions based on median numbers of number and duration of sessions. The MMi acknowledged the losses and life threat, examined critical past challenges, and reinforced commitment to life goals. At post-test, participants significantly improved in self-	Absence of CG and attention CG. Small sample size hindered variability in patient characteristics and affected generalizability. Variable intervention format might have affected effectiveness.

Study, Location	Purpose & Patient population	Study design	Sample size (n) & characteristics	Study conditions	Main findings	Main limitations
	curative or palliative care.				esteem and reported greater sense of security.	
Lee et al. 2006b [249]; Canada	To prospectively examine the efficacy of MMi on positive indicators of psychological well-being compared to usual care Patients with breast or colorectal Ca (within 6 m post-diagnosis) at four university hospitals	RCT stratified by Ca site One baseline and one post-intervention (within 24 h after last session) assessments	n=74 (35 IG – 39 CG) IG: Age: 56.4±9.8 y; 80% Females; 63% Married; 62% Employed; 66% Breast Ca CG: Age: 56.9±10.1 y; 82% Females; 66% Employed; 67% Married; 74% Breast Ca Breast Ca: 77% Stage I or II disease Colorectal Ca: 82% Stage III or IV disease	<u>Intervention:</u> Up to four individualised sessions in the patient's home or clinic that promoted self-exploration of impact and meaning of cancer diagnosis, past significant life events, and life priority and goal changes. <u>Control:</u> Usual care only.	After controlling for baseline scores, participants in the IG demonstrated significantly higher levels of self-esteem, optimism and self-efficacy. The associated effect sizes were only small: Self-esteem $d=0.26$; optimism $d=0.24$; self-efficacy $d=0.22$.	Generalizability limited due to small sample size and overrepresentation of patients with breast Ca. Attrition and selection bias possible. Variable intervention format and delivery conditions might have affected effectiveness.
Lethborg et al. 2012 [251]; Australia	To examine the themes arising from MaP therapy sessions in relation to therapeutic goals, and to describe participant acceptability of MaP therapy Patients with advanced cancer (stages III and IV) receiving outpatient palliative treatment	Prospective, pseudo-experimental, one group One post-intervention assessment point	n=6 Age: 61 (39-86) y 3 Females 3 Breast Ca, 2 Brain Ca, 1 Lymphoma, 1 AML, 1 Colon	<u>Intervention:</u> A four-session, individual, face-to-face therapy using methods influenced by narrative therapy, meaning-based coping theory, existential therapy and cognitive therapy to enhance general and illness-related meaning-making.	Thematic analysis of each session revealed the MaP therapy encouraged reflection, offered insights and allowed participants to focus onto meaningful goals. Acceptability of intervention was supported as patients described it as positive, comfortable, surprisingly deep, and enjoyable if limited to four sessions.	Study design insufficient to adequately support effects of intervention. Detection bias possible given that outcome assessor was the therapist delivering the intervention. Small sample size.
Notes: Ca – Cancer; y – Years; m – Months; d – Days; mins – Minutes; CT – Chemotherapy; QOL – Quality of Life; MaP – Meaning and Purpose; AML – Acute Myeloid Leukaemia; IG – Intervention Group; CG – Control Group; MMi – Meaning Making Intervention; IMCP – Individual Meaning-Centred Psychotherapy; TM – Therapeutic Massage; MCGP – Meaning Centred Group Psychotherapy.						

Table 2.3. Summary of characteristics of the 18 studies implementing a qualitative methodology

Study, Location	Purpose & Patient population	Study design & Sampling	Sample size (n) & characteristics	Interviews & Method of analysis	Main findings	Main limitations
Arman and Backman 2007 [276]; Sweden	To examine experiences of life among women with breast Ca during a 1-year follow-up on three occasions (enrolment, 6 m and 12 m), and to explore diversity of profiles among women in anthroposophical and conventional care. Women with breast Ca at various disease stages.	Longitudinal Comparative Convenience sampling Part of a larger study	n=74 (37 matched pairs) Age: 48 (28-75) y; 54% Recurrence or metastatic disease; Time since diagnosis: 24 (1-131) m	Three rounds of semi-structured interviews using three open-ended questions. Qualitative content analysis	Important changes noticed at 1 y: appreciation of the beauty of life, experiences of threat, changes in the body, and introspection into self and meaning in life. Anthroposophical group: more orientated towards personal growth and meaning in life; Conventional care group: more orientated towards external activities and bodily changes.	Limited comparability with studies of patients with breast Ca, where time since diagnosis was shorter or more homogenous.
Boehmke et al. 2006 [253]; USA	To gain a better understanding of the common meanings and shared experiences that women encounter after a diagnosis of breast Ca. Newly diagnosed women with breast Ca during their last cycles of CT.	Cross-sectional Purposive, convenience sampling Secondary analysis of data from a larger study	n=30 Age: 47±7.8 (33-68) y; 100% Caucasian; 73% Married; 13 Stage II disease, 17 Stage III disease	Individual interviews in private cubicles in the recruiting centre. Heideggerian hermeneutical analysis.	Four themes emerged: Changing health overnight; Erasing of a former self; Appraising of illness; and Approaching the future – now what? The constitutive pattern was transitioning from health to illness.	The social support network of participants was not examined.
Burles and Holtslander 2013 [254]; Canada	To explore women's lived experiences of ovarian Ca, and investigate how they negotiate and make sense of illness-related issues. Women with ovarian Ca (≥6 m post-diagnosis).	Prospective Convenience community-based	n=16 Age: 52 (37-68) y; 10 Married/partnered; Various disease stages; 7 One or more recurrences; Time since diagnosis: 9 m-13 y	In-depth face-to-face interviews and additional (13 participants) serial follow-up e-mail interviews every 2 w for up to 12 w (total 51 e-mail interviews). Hermeneutic phenomenological analysis.	Five broad themes emerged: changes in health status and the body; disruptions to everyday activities; shifts to relationships; uncertainty; and coping and finding meaning in illness. These themes constitute the essence of living with ovarian Ca, 'cautious optimism'.	Relatively homogenous sample. Some of the women also participated in Ca support groups.

Study, Location	Purpose & Patient population	Study design & Sampling	Sample size (n) & characteristics	Interviews & Method of analysis	Main findings	Main limitations
Ching et al. 2012 [257]; China	To explore the process of coping on Chinese women with breast Ca. Women with early stage breast Ca at different treatment phases.	Prospective Theoretical sampling	n=24 Age: 15 women 40-59 y; 17 Married; 12 Newly diagnosed prior to surgery, 12 Receiving RT±CT±HT	Thirty five in-depth interviews (30 mins-3 h) in the patients' homes or in hospital rooms. Five women were interviewed 3 times from diagnosis to 3 m post-treatment. Grounded theory.	Reframing was identified as the key category in the adjustment process, through which the women identified meaning at different points in the Ca experience to achieve different meanings. The women identified a sustaining force from minimising social disturbance during treatment.	Findings might not be transferrable to different cultural contexts.
Dazio et al. 2009 [261]; Brazil	To analyse the meanings attributed to the disease experience and treatment among men with intestinal stoma. Men with colorectal Ca and a temporary or permanent stoma for at least 1 m.	Cross-sectional Convenience sampling	n=16 Age: 13 men 51-79 y; 10 Married; 13 Rectal Ca; 12 Permanent stoma; Time since stoma formation: 1 m-7 y	Serial (2) semi-structured interviews (60 mins) and participant observation in the patients' homes and in the hospital. Ethnography, inductive data analysis.	Two groups of meanings were selected: acknowledging the severity of the disease and the distress of having Ca, and being submitted to surgery and suffering from a stoma.	Concepts are not fully developed analytically, although some information is provided regarding theoretical and methodological underpinnings of the study.
Evans et al. 2012 [262]; UK	To explore 'holistic assessment' to give patients the opportunity to describe their illness experiences. Patients with Ca at two centres offering a range of CAM therapies.	Cross-sectional Maximum variation sampling	n=34 Age: 53 (24-82); 25 Females; 26 Married/partnered; 14 Breast Ca, 7 Gynaecological Ca; 3 Lung Ca, 3 Lymphoma, 2 Prostate Ca; 2 MM; Time since diagnosis: 20 <6 m.	Non-participant observation and interviews with staff and patients. Ethnography through narrative	A typology of stories emerged: 'factual', 'emotional' and 'moral', with overarching processes common to all: loss, uncertainty and conflict, embracing or resisting change. Stories provided a 'window' into patients' inner experiences.	Theoretical and philosophical underpinning of the study not mentioned.
La Cour et al. 2009 [277]; Denmark	To explore and understand how people with advanced Ca create meaning and handle life through activity. Patients with lung Ca, colon Ca or breast Ca.	Cross-sectional Purposive sampling Part of a larger study	n=7 Age: 39-67 y; 5 Females; 3 Lung Ca, 2 Breast Ca, 2 Colon Ca	Twelve qualitative interviews and participant observations over a period of 18 months in the participants' home	A central narrative was identified as the meta-narrative of 'saying goodbye in a good way'. Three smaller narratives evolved and were identified as 'I am healthy although I am sick',	Literature review missing some information.

Study, Location	Purpose & Patient population	Study design & Sampling	Sample size (n) & characteristics	Interviews & Method of analysis	Main findings	Main limitations
				environments. Narrative emplotment and reasoning of narrative.	'routines and continuity as a platform for agency' and 'my little Mecca'.	
Lethborg et al. 2006 [278]; Australia	To explore how participants experience and apply meaning through an integrated framework of assumptive world, sense of coherence and meaning-based coping. Patients with advanced Ca (Stage IV) with an estimated prognosis of 6-12 m.	Prospective Purposive sampling	n=10 Age: 58 (36-78) y; 5 Females; 7 Married; 4 Breast Ca, 3 Lymphoma, 2 Colon, 1 Melanoma; Time since diagnosis: <1-20 y	Sixteen semi-structured interviews: 10 upon recruitment; 6 three m after the first. 26 Conversations in total. Thematic analysis.	Three interrelated domains (experiencing the reality of advanced Ca; responding to the impact of advanced Ca; living life fully with continued meaning) formed a pathway towards coherence and sense of self. This linear pathway is also responsive to the on-going stressful nature of advanced Ca.	Additional causes of terminal illness were not examined.
Lin 2008 [279]; Taiwan	To explore the experiences of searching for meaning in life. US-resident Chinese immigrants with metastatic Ca.	Cross-sectional Purposive sampling	n=12 Age: 37-70 y; Breast, Lung, Nasopharyngeal, Ovarian, Leukaemia, Colon, Liver, Brain Ca; Time since diagnosis: 1 m-5 y; Length of stay in the US: 3-50 y	Three-part in-depth, unstructured interviews: life history, present life experience, meaning. Narrative analysis.	Six themes emerged: suffering and impending death, compassion and love, joy and value, hope and faith, readjustment and transcendence, and empowerment and peaceful dying. Although participants simultaneously faced suffering, they searched for meaning in their lives.	Cantonese-speaking only patients were not included in the sample.
McCaughan and McKenna 2007 [258]; UK	To explore the information-seeking behaviour of patients newly diagnosed with Ca in the immediate post-diagnosis period. Newly diagnosed out-patients with Ca within the first 3 m post-diagnosis.	Cross-sectional Theoretical sampling	n=27 Age: 45-93 y; 14 Females; Lung Ca, Breast Ca, Colon Ca, Thyroid Ca, Prostate Ca, Bone Ca, Kidney Ca; Wide range of educational levels	In-depth interviews (50-75 mins) in the patients' homes. Grounded theory.	The proposed theory described the transitions from 'being traumatised' by the diagnosis, through a phase of trying to 'take it on', through to 'taking control'. Patients' information-seeking behaviour seemed a journey of 'never-ending making sense' with on-going discovery and new information needs.	No in-depth examination of the stage of 'taking control'. No gender differences in behaviours were explored. Selection bias possible due to medical staff assessing patients' ability to participate.

Study, Location	Purpose & Patient population	Study design & Sampling	Sample size (n) & characteristics	Interviews & Method of analysis	Main findings	Main limitations
McGrath 2004 [50]; Australia	To examine the notion of spirituality and spiritual pain, and explore aspects of spirituality. Survivors of haematological malignancies (≥3 y post-diagnosis).	Cross-sectional Convenience sampling Part of a larger study	n=12 Age: 25-60 y; 8 Males; 5 CML, 3 ALL, 2 AML, 1 MM, 1 Non-Hodgkin's lymphoma; 12 High-dose RT+CT; 8 BMT; Time since diagnosis: 3-15 y	Open-ended interviews in the patients' homes or in comfortable meeting places. Phenomenology.	The results indicated increased confidence and assertiveness, less dependence on the approval of others, increased awareness of body needs. The positive outcomes included the gift of extra life, the desire to live life to the fullest and a stronger sense of family togetherness.	Selection bias possible as participating patients all had positive treatment outcomes and had been well supported.
Prior 2009 [263]; Australia	To explore why Aboriginal women appear reluctant to following-up results or accept medical advice. Aboriginal women Ca survivors, family members, healthcare providers and other women from the community.	Cross-sectional Convenience and purposive sampling	n=48	Fieldwork, participant observation, face-to-face interviews and focus groups over 2 y in two Aboriginal communities. Ethnography	Women had a fearful and fatalistic attitude towards Ca, and doubted the efficacy of treatment. The women faced a dilemma of wanting access to Ca treatment, but feared entering hospital not attuned to their cultural needs.	No demographic/ clinical variables were reported for the sample to enhance interpretation of transferability.
Quinn 2005 [280]; UK	To explore the search of meaning in people living with Ca. Patients with Ca at various disease and treatment stages.	Cross-sectional Convenience sampling	n=9 5 Females; Leukaemia, Lymphoma, Breast Ca, Testicular Ca, Ovarian Ca; 2 Terminal disease	Open-ended interviews. Hermeneutic phenomenology.	The search of meaning is on-going; multifaceted and may be lived out in a variety of ways; living with Ca and the treatment brings many changes some of which lead to a sense of loss of control.	Reporting of methodological aspects of the study is poor.
Röing et al. 2009 [255]; Sweden	To explore what it might mean to live with the consequences of oral Ca. Patients with oral Ca in one University hospital.	Cross-sectional Convenience sampling Part of a larger study	n=5 Age: 61 (48-81) y; 3 Males; 2 Floor of the mouth, 1 tongue, 1 maxilla, 1 gingiva; 5 RT; Time since start of treatment: 4 y	Semi-structured interviews (60-90 mins) in the patients' hospital. Hermeneutic phenomenology.	The consequences of oral Ca affected the being-in-the-world of the participants in three ways: existing as oneself; existing in the eyes of others; and existing with others.	Researcher was familiar with the nature of oral cancer, probable source of bias

Study, Location	Purpose & Patient population	Study design & Sampling	Sample size (n) & characteristics	Interviews & Method of analysis	Main findings	Main limitations
Sarenmalm et al. 2009 [259]; Sweden	To explore the main concerns of women with recurrent breast Ca, and how they deal with their situations. Women newly diagnosed with recurrence of breast Ca.	Cross-sectional Prospective Purposive sampling Part of a larger study	n=20 Age: 55-81 y; 13 Married; 17 Distant metastases; Median time from diagnosis to recurrence: 68 weeks	Forty in-depth serial interviews (90-150 mins) between 2 weeks and 24 m (12 participants) and between 3 and 6 m (8 participants) post-recurrence. Grounded theory.	The core category illustrated the process of 'making sense of living under the shadow of death', and was based on the women's experiences of adjusting to living with a persistent life-threatening disease.	Selection of patients for interviews at different time-points was not justified. Selection of the 20 patients out of 56 from the original study was not justified.
Tang et al. 2007 [260]; China	To examine psychosocial difficulties faced by Chinese patients with colorectal Ca, and to identify factors that contribute to the meaning searching process. Patients with colorectal Ca (within 2 y post-diagnosis).	Cross-sectional Convenience sampling	n=26 Age: 54.5 (28-75) y; 19 Males; 88.5% Married; 65.3% Stage III or IV disease; 81% CT, 15% RT; 31% Stoma	Individual semi-structured in-depth interviews (60-90 mins) in private counselling rooms. Constant comparative analysis.	Two domains of psychosocial disorientation states were identified: cognitive disorientation and emotional disorientation. Factors that facilitate meaning searching were categorised into personal factors and external factors.	No assessment of respondents' emotional and cognitive responses right after the diagnosis of Ca, retrospective nature of collected data
Thomé et al. 2004 [256]; Sweden	To investigate the meaning of living with Ca in old age. Patients with Ca aged ≥75 who had just previously completed treatment.	Cross-sectional Convenience, consecutive sampling	n=10 Age: 75-88 y; 6 <6 m post-diagnosis; 4 Relapse; Gynaecological Ca, Lung Ca, Colon Ca, Prostate Ca, Breast Ca, Oral Ca	Individual in-depth interviews (45-150 mins) in the patients' homes. Hermeneutic phenomenological analysis.	Four overarching essential themes: transition into a more or less disintegrated existence; sudden awareness of the finiteness of life; redefinition of one's role in life for good and for bad; meeting disease and illness.	Variability of diagnoses and stages of illness
Notes: Ca – Cancer; y – Years; m – Months; d – Days; mins – Minutes; CT – Chemotherapy; RT – Radiotherapy; HT – Hormonal therapy; QOL – Quality of Life; CAM – Complementary Alternative Medicine; CML – Chronic myeloid leukaemia; ALL – Acute lymphoblastic leukaemia; AML – Acute myeloid leukaemia; MM – Multiple myeloma; BMT – Bone marrow transplantation;						

Global meaning (including Existential meaning/Meaning in life)

Only limited research focussed on investigating global meaning as a whole in patients with cancer, given that only five articles were retrieved reporting results on three original studies [192, 202, 244, 245, 264]. These studies employed correlational designs to specifically explore dual relationships between global meaning and specific health aspects such as psychosocial distress or physical health. In the context of breast cancer, two studies concluded that greater global meaning may be linked to lower distress, improved QOL and fewer breast cancer problems [192], and that global meaning may constitute a partial mediator for psychological response and adjustment to illness [264]. Conversely, in a wider cancer population (28% with a haematological condition), it was the physical aspects of cancer that were found to indirectly affect global meaning over the cancer trajectory [244, 245], whereas among patients with advanced cancer global meaning was also influenced by the perceived social support and existential distress [202]. Whereas there is a clear indication for a link between global meaning and several behavioural variables, the direction of this association is yet to be confirmed.

A number of studies specifically endeavoured to address the role of existential meaning or meaning in life for patients with cancer [50, 202, 241-243, 265, 269, 270, 273, 274]. To date, current evidence derives primarily from correlational studies that examined relationships between existential meaning and parameters such as psychological adjustment, levels of distress and coping strategies, and from studies testing interventions to promote meaning in life. One of the most popular relationships investigated in the correlational studies was that between meaning in life and psychosocial adjustment [202, 241-243, 265, 269, 270, 273, 274]; yet, the level to which meaning can predict cancer-related distress still remains unknown, as evidence is inconclusive. Meaning in life was found to predict higher QOL in women with breast cancer [273] and psychosocial well-being in patients with testicular cancer [269], but, unlike findings from other studies [202, 243], there was no significant relationship between meaning in life and cancer-related distress [269]. A mediating role for meaning in life in the relationship between social functioning and distress was also proposed [241, 242], whereas among cancer survivors low levels of meaning were directly linked to higher levels of depression [274]. Of note, different socio-demographic characteristics might influence construction of meaning in life and the associated levels of distress. During survivorship after breast cancer, a comparative study concluded that personal meaning in life was lower and psychological distress higher in those survivors who had children [265]. No similar findings were reported in the healthy group, which offers preliminary evidence for a potentially unique effect of parity on existential findings for women with breast cancer. Similarly, survivors of haematological malignancies described the positive aspects of their experience, including the

gift of extra life, a desire to live life to the fullest and a stronger sense of family togetherness [50]. This hypothesis warrants further testing. Conversely, no significant relationships were found between age or educational level and meaning in life [269]. Whether this result implies that meaning can be considered to be a universal phenomenon, may be too naïve a conclusion and requires explicit future research. Furthermore, patient coping strategies (either adaptive or maladaptive) and the presence of meaning in life also seem to be linked [241-243, 270], but the evidence is not always supportive of this relationship [273]. Specifically, the presence of meaningfulness was associated with better coping efficacy [243] and, in fact, coping styles such as acceptance, positive reinterpretation, and active coping were linked to positive life meaning, while the absence of these coping strategies was associated with negative meanings such as loss [241]. Along these lines, a positive relationship between lack of meaning in life and negative health behaviour changes was found among survivors of cancer [270]. Finally, meaning in life was also linked to the experience of physical symptoms such as fatigue, but evidence regarding this remains inconclusive [275].

To further clarify the links between existential meaning and patient adjustment, a number of trials investigated the potential effects of individualised meaning-making interventions on the making-sense process itself, as well as on behavioural variables such as patient QOL or well-being. Despite wide variability in the actual intervention and its duration, type and stage of cancer, and targeted outcomes, evidence generally seems to favour the experimental condition. Specifically, interventions involving psychotherapeutic sessions were shown to promote goal setting and enhance patients' sense of coherence, with meaning attribution perceived as being beneficial [251]; enhance meaning in life in women with advanced cancer with significant increases in overall QOL and existential well-being [246, 248]; significantly and positively impact self-esteem, optimism and self-efficacy in patients with breast or colorectal cancer [249, 250]; improve spiritual well-being and sense of meaning in the context of end-of-life care, with improvements persisting even two months post-intervention [246, 252]; and exert positive effects on symptom-related distress [246]. Conversely, when expressive writing was used as an indirect way to promote the search for meaning, a pseudo-experimental study concluded that there was no significant association between meaning-making and physical health outcomes [247]. Despite the fact that no specific intervention was tested, a Swedish study provided insight on whether the additional use of complementary therapies might prove helpful in creating meaning in life one year after breast cancer diagnosis [276]. Participants who used complementary therapy experienced self-introspection and a sense of meaning in life, which was described in a variety of ways, from trivial everyday activities to interpersonal relationships, through recreational activities such as sports, and art [276].

Meaning of illness (as part of Situational meaning)

In general, research regarding the meaning of cancer as an illness has not received much attention due possibly to its susceptibility to contextual influences. Of note, whereas three relevant studies conducted with patients with haematological malignancies were published until 2003 [49, 51, 52], only two more were retrieved during the updated searches [50, 280]. As stated previously, widely diverse quantitative studies provide some insight to this area. For instance, among cancer survivors, over half of the sample perceived illness as a challenge (52%), but fewer as value (38%) or as irreparable loss (35%) [266]. Two years post-diagnosis on average, patients with lung cancer who found positive meaning in their illness perceived it as a challenge or as a value [272], while those ascribing negative meaning were found with significant deficits in QOL [272]. In a similar patient group, where illness was perceived as manageable, higher levels of QOL were evident [108]. Moreover, the more negative meanings of cancer (e.g. interruption, loss, threat) were associated with avoidance coping strategies, anxiety and depression, whereas the more positive interpretations (e.g. challenge, value) were linked to adaptive coping [266]. Meaning of illness can also be predictive of adjustment in patients with cancer; nevertheless, evidence is limited to draw safe conclusions. Even so, when controlled for different sociodemographic variables, negative meaning of illness was a significant predictor of poorer adjustment of women experiencing ovarian cancer [271]. Along these lines, constructed meaning was proposed to have a positive impact on self-perception and therefore an indirect impact on illness adaptation [268], but it still remains to be answered whether the reverse of this relationship is also true.

From a qualitative point of view, available studies offer additional significant insight on what the meaning of cancer is for the affected individuals. Different perspectives, both positive and negative, were identified as patients attempted to describe their experiences. Boehmke and Dickerson [253] reported on three different strategies that women with breast cancer employed when appraising the illness: thinking in a positive way, thinking that it is an illness that they have to deal with and as a loss [253]. Nevertheless, cancer perceived as a loss of previous capacity was a consistent theme across studies [253, 255, 256, 259, 278]. For example, among patients with oral cancer, existential distress in their efforts to see themselves in the world was expressed through a loss of language [255]. Conversely, in the context of advanced cancer, patients experienced illness through their fear of death and a sense of isolation [259, 278]. Of note, such interpretations may be dependent on the patients' previous views of the world or what was important in their life prior to illness [256]; however, it is still uncertain whether the effects of past worldviews on the meaning of illness are similar in the younger patient population or refer exclusively to older people with cancer [256].

Meaning-making as a process (as part of Situational meaning)

A number of correlational and qualitative studies also investigated the process of meaning-making within the context of cancer, either through exploration of influential factors, such as gender, age, type of relationship and affect, among the different elements of the process of meaning-making, or through qualitative accounts that offer a more in-depth understanding on the nature of such a process.

Collectively, quantitative evidence posits that patients' making-sense process can be characterised from their searching for a cause [254, 261, 263]. Patients' causal attributions may be influenced by previous lifestyles [254, 261, 263], religious beliefs [254, 261, 263] or cultural backgrounds [263]. An active search for meaning may also be indicated by patients asking themselves "why me?", or by their efforts to make sense of daily events [280]. Importantly, meaning-making can be an on-going process that does not stop or fades away as time elapses. On the contrary, it may persist even after certain periods have come into conclusion, such as after completion of anticancer treatment [266, 280]. In this endeavour, factors such as age or time since diagnosis can have an impact on meaning-making and vulnerability; indeed, younger age and shorter time post-diagnosis were significant predictors of both increased meaning and vulnerability among women with breast cancer [240]. Alternatively, perceptions of positive meaning may be associated with higher levels of positive affect [240] and in other cases may be directly related to growth and meaning in life [204]. However, not only the positive but also the negative consequences of the meaning-making process should be acknowledged. Longitudinal data from a sample of women with breast cancer indicated that the actual search for meaning was correlated with greater negative affect, thus supporting the idea that it can be a distressing process that does not necessarily lead to meanings made [203].

Qualitative evidence sheds even more light on the complexities of the meaning-making process for people with cancer and its impact on their efforts to assume control throughout their cancer journey [258]. To illustrate this point, patients' sense-making process has been proposed to involve several different pathways from disorientation to transformation [260]; entail a transition from health to illness that takes place in three stages: confrontation, easing distress and transcendence [259]; or includes the telling of three different types of tales: emotional, factual and moral ones [262]. Clearly, these non-exhaustive approaches of meaning-making reveal a fundamentally complex process that may be as subjective and unique as each person is. In order then to reconstruct the meaning of their current condition and/or reframe their experience of cancer, patients might use meaning-making coping through

acceptance, sustenance and integration [257], or rely on different relational (e.g. family support, social network) or internal sources (e.g. positive thinking, reappraisal of life) [260], or everyday activities such as gardening [277] to manage the cognitive and emotional challenges.

The current review of the literature attempted to update the knowledge pertinent to the field of meaning-making by including the most recent (published in the last decade) studies in the cancer care context; several findings are worth mentioning. Firstly, the meaning-making process component remains the most investigated part of Park and Folkman's meaning-making model [11, 14], similarly to what Lee et al. [231] claimed ten years ago. However, once again, research is skewed towards the more positive implications of meaning-making, thus rendering data on the more negative ones relatively sparse. Secondly, research on global meaning, including the aspects of existential meaning or meaning in life, has increased significantly over the course of this decade. Yet, studies focussing exclusively on global meaning per se (and not in one aspect of it, i.e. existential meaning) still remain limited. Finally, Lee et al. [231] stressed the lack of and the need for more experimental studies, which are present in the current review. This improvement is significant considering the preliminary positive results obtained. However, as the majority of the published trials were in their pilot or feasibility phases, research in this domain remains in its infancy.

2.4 Making sense in the context of cancer – the family caregiver perspective

The importance of the roles of family caregivers in the support of patients diagnosed with cancer (or other chronic illnesses) has already been highlighted in this thesis (see Section 1.3). Given that cancer affects not only those diagnosed but also their families [9, 281], it is reasonable to hypothesise that family members, like patients, may attempt to seek and create meaning of their indirect illness experience and their direct involvement in the care of their loved one. Hence, in this section, the literature regarding how family caregivers create meaning is presented in order to gain some insight on the focus and gaps of the relevant empirical research. The initial aim was to present evidence pertaining to the context of cancer solely; however, a systematic search strategy in several electronic databases (Medline, Embase, Web of Science, CINAHL) revealed only eight articles published between 1997 and 2012, thus suggesting a dearth of research in this area (for detailed information regarding the

search strategy see Appendix 2). Therefore, in order to gain a better understanding of meaning-making attempts of family members in caregiving roles, the scope of the review was expanded to include research conducted in different chronic illness contexts. Despite some growing evidence in the context of paediatrics, such studies were not included in this review, as the main purpose was to present data from family caregivers of adult patients.

The search yielded 26 relevant papers. Of these, two were review papers [282, 283], one reported a tool development [218], one was a personal account [284], and five reported findings on parents' making-sense [215, 285-288]. Therefore, these nine papers were excluded from this review. Summaries of the main characteristics of the final sample of 15 original studies (17 articles) are presented in *Table 2.4*. Eight original studies (nine articles) were retrieved that focussed on some aspect of meaning from the family caregiver's perspective in non-cancer contexts. Family caregivers in these studies were caring for elderly patients [289, 290], patients with multiple sclerosis (MS) [217], HIV/AIDS [291], Alzheimer's disease [292], amyotrophic lateral sclerosis (ALS) [293], myocardial infarction [294], or a combination of conditions [295, 296]. The majority (n=6) of these studies employed a qualitative methodology. Seven additional original studies (eight articles) investigated aspects of meaning in family members of patients with a cancer diagnosis. Of these, five were conducted in the acute phase of the cancer trajectory [108, 297-300] and three in the end-of-life and bereavement phase [301-303]; only two studies employed a quantitative methodology in their design [108, 298]. Due to substantial diversity in the identified studies, only a narrative synthesis of data was feasible. Nevertheless, findings were clustered and presented according to the specific component of Park and Folkman's meaning-making model [11, 14] that each study attempted to address.

Table 2.4. Summary table of the 15 original studies reporting on the making sense of family caregivers (cancer and non-cancer context)

Study, Location	Purpose, Population & Health Context	Study design & Sampling	Sample size (n) & characteristics	Main findings	Main limitations
Ayres 2000a [295], Ayres 2000b [296]; USA	To explore the variety of meanings caregivers brought to and made from their experiences, and to describe the components of meaning-making. Family caregivers of physically and/or cognitively disabled adults and teenagers. Chronic illness/disability – various diagnoses.	Cross-sectional, exploratory, qualitative Maximum variation	n=36 Age: 56% 45-65, 28% >65 (39-92) y; 25 Females; 27 Caucasian; Relationship to patient: 50% Parent, 39% Spouse, 17% Child; Length of caregiving: 47% 2-5 y, 22% ≤1 y.	Caregivers told four types of stories: stories of ideal lives, stories of ordinary lives, stories of compromised lives, and ambiguous stories. The process of meaning-making included three interrelated components: expectations (predictions for events or behaviours), explanations (moral and practical reasoning), and actions taken to actualise explanations.	Thematic and narrative analysis of data may have prevented in-depth interpretation.
Cadell and Marshall 2007 [291]; Canada	To explore how individuals self-construe themselves in relation caregiving for a person with HIV/AIDS and as an intimate partner after the loss of a partner. Gay or transsexual caregivers who had lived through the death of a partner to HIV-related causes. HIV/AIDS – bereavement.	Cross-sectional, exploratory, qualitative Part of two larger studies Convenience	n=7 6 gay males, 1 heterosexual male-to-female transsexual; 4 HIV-positive; Time since death of partner: 1-10 y.	Caregivers described themselves as part of partners' identity – caregiving became a part of the self as well as aspects of the partner. Upon the death of the partner, the loss resulted in a crisis of meaning due to the loss of the person and relationship that had contributed significance and purpose to life. Regaining meaning involved making sense of both the relationship and the caregiving role.	Retrospective design limits conclusions regarding transformations in self-construals as no analysis of intra-individual change was possible.
Down-Wamboldt et al. 2006 [108]; USA	To explore the relationship between meaning of illness, perceived social support, coping strategies and QOL, and to investigate between-group differences in these variables Family members of patients with lung Ca NSCLC – within 6 m post-diagnosis	Cross-sectional, correlational, comparative Convenience	n=85 dyads Family members: Age: 57.6±12.4 y; 72% Females; 98% Caucasian; 86% Married; 64% Spouse, 20% Child, 16% Other	For family members, regression results indicated meaning of illness perceived as less adverse impact as the strongest predictor (25% of variance) of QOL. Family members had better psychological and spiritual satisfaction were higher in the family members compared to patients.	Fear of recurrence was not examined as potential covariate. Regression models were not adjusted for demographic/ clinical covariates.
Finch and Gibson 2009 [297]; UK	To explore how young people experience learning about their parent's Ca diagnosis. Young people (14-18 y) within 4-12 m post-diagnosis of their parent. Breast or haematological Ca – newly	Cross-sectional, exploratory, qualitative Purposive	n=7 Age: 14-18 y; 4 Males; Parent with Ca: 4 Mother; Parent's diagnosis: 4 Breast, 2 NHL, 1 AML; Time since diagnosis: 4-	Six dimensions of the young person's experience were revealed: first hearing about a parent's diagnosis; vulnerability of self and others; communication within the family; feeling supported in experience; experience and support of school; and experience and support of hospital.	Unknown life events that young people might have been experiencing were not taken into account. Differences in the parents' experience of illness based

Study, Location	Purpose, Population & Health Context	Study design & Sampling	Sample size (n) & characteristics	Main findings	Main limitations
	diagnosed		11 m		on the type of Ca.
Kellett 1998 [289]; Australia	To explore the experiences of providing care in nursing homes. Family members providing care for an older relative. Aging/frailty.	Cross-sectional, exploratory, qualitative (interviews and participant observation) Convenience	n=14 Age: 41-74 y; 9 Females; 10 Married; Relation to care recipient: 5 Spouses, 5 Daughters; Duration of caregiving at home: 3-6 y; at nursing home: 1-6 y.	Six themes of meaning were generated: sense of family life past (family closeness and belonging); sense of break (feelings of 'homelessness'); sense of change in engaged involvement (sense of role loss); sense of worth (processing special knowledge/being experts in the care of the relative); sense of concern (being out of control/not being heard); and sense of continuity.	Unclear data analysis process. Caregiving duration varied (3-6 years)
Kim et al. 2008 [298]; USA	To examine how attachment qualities relate to caregiving motivations, and how different caregiving motives relate to differences in psychological adjustment. Adult spousal caregivers of survivors of Ca. Mixed Ca types – survivorship.	Cross-sectional, exploratory, correlational Convenience	n=314 Age: 56.5±10.6 y; 51% Wives; 91% Caucasian; Time since the patient's diagnosis: 2.2±0.6 y; 51% provided active care.	Attachment security related positively to autonomous motives for and finding benefit in caregiving. Among husbands, autonomous motives were also related to less depression. Among wives, autonomous motives were also related to greater benefit finding.	Cross-sectional nature precludes directionality to be established. Moderating effects of caregiver characteristics were not included in analyses.
Manne et al. 2009 [300]; USA	To evaluate the role of cognitive processing and social modulation of cognitive processing in predicting partners' distress responses to breast Ca. Partners of women diagnosed with early stage (I-IIIa) breast Ca. Early stage breast Ca	Longitudinal, descriptive, correlational Convenience	n=253 Age: 51.2±11.2 (26-80) y; 91% Caucasian; 97% Males; 95% Married; Relationship length: 22 (2-57) y; Patient disease stage: 36% I, 51% II, 3% IIIa; Patient treatment post-surgery: 87% CT	Lower satisfaction with partner support predicted greater global distress, and greater use of positive re-appraisal was associated with greater distress. Partners who did not report finding meaning in the patient's cancer reported greater cancer-specific distress than those who reported having found meaning.	Low participation rates may have resulted in a non-representative sample. Retention rates in the study were relatively low and might have biased results.
Mock and Boerner 2010 [293]; Canada	To examine the associations of sense-making and benefit-finding with depressive symptoms. Patients with ALS and primary caregivers. Outpatient care for ALS.	Cross-sectional, correlational, quantitative Convenience	n=52 dyads Caregiver age: 55.9±12.7 y; Caregivers: 71% Females; Time since diagnosis: 44±26 m; Type of relationship: 79% Spouses, Parent/child	Benefit-finding, but not sense-making, was associated with fewer depressive symptoms for both patients and caregivers. Patient and caregiver dyads where neither found benefit had more depressive symptoms compared to pairs where at least one member found benefit. Caregivers were more likely to cite finding personal strength as a benefit.	Cross-sectional nature precluded directionality of relationships to be established. No adjustment for patient, caregiver, dyad characteristics.

Study, Location	Purpose, Population & Health Context	Study design & Sampling	Sample size (n) & characteristics	Main findings	Main limitations
			15%.		
Pakenham 2008 [217]; Australia	To determine the dimensional structure of sense-making, investigate relations between sense-making and both positive and negative adjustment outcomes. Informal caregivers of patients with MS. MS – mixed disease severity and duration.	Prospective, repeated measures, correlational Convenience	n=232 Age: 52.4±13.4 (17-87) y; 64% Males; 83% Married; 53% Employed; Duration of caregiving: 9.2±7.6 (1 m-46 y) y; 79% Spouse, 13% Family member, 8% Friend.	Factor analysis revealed six dimensions of carer sense-making: catalyst for change; acceptance; spiritual perspective; incomprehensible; relationship ties; and causal attribution. Controlling for baseline adjustment and demographic/clinical characteristics, sense-making factors predicted adjustment 12 m later (i.e. life satisfaction, positive affect, anxiety, depression).	Low response rate affected sample representativeness. No inferences on the causal direction between sense-making and adjustment could be made.
Panagopoulou et al. 2009 [294]; Greece	To explore the process of dyadic benefit finding after MI. Patients treated for MI and their spouses. MI – post-discharge from intensive care.	Cross-sectional, exploratory, dyadic, qualitative Convenience	n=11 dyads Partner age: 45-64 y; Caregivers: 8 Females; Duration of marriage: 15-22 y.	Two major themes emerged for spouses: active search for benefit/failure to find benefit and improvement of relationship. The majority of partners were engaged in deliberate attempts to identify positive aspects in the experience, although they were not always able to identify benefits. Other partners reappraised the absence of worse outcomes as a benefit itself.	Questionable whether interpretative phenomenological analysis appropriate for dyadic analysis of qualitative data.
Paun 2003 ; USA [292]	To explore the experience of caregiving, and what it means to be an older woman carer of a spouse with AD. Older women (≥60 y) providing home care for ≥3 y for a spouse requiring assistance with at least two activities of daily living. AD or related dementia – no specific context was reported.	Cross-sectional, exploratory, qualitative Purposive	n=14 Age: 72 (60-82) y; 9 Caucasian, 5 African American; Duration of marriage: 46.5 (25-56) y; 12 Full-time employed.	Making sense of the women's situation was not a permanent state of mind. Emerging themes included: concrete formulations about AD; counting losses and blessings; defining self and spouse within the context of the AD experience; revisiting the marital relationship; exploring commitment and choice in relation to caregiving; expressing beliefs and values in life; and placing the experience in a life-long perspective.	Possible sampling bias towards caregivers who used at least one form of formal support – transferability limited.
Skerrett et al. 1998 [299]; USA	To explore how a diagnosis of breast Ca affects the marital relationship, and to determine how various aspects of the relationship assist or impede couple adaptation. Married couples within 18-31 m post-diagnosis of breast Ca.	Cross-sectional, exploratory, qualitative Part of a larger study Convenience	n=20 couples Age: 75% 45+ y; Duration of marriage: 60% 25+ y	Optimal coping functioning depended on the couple's ability to define the experience as 'our' problem. Couples having a more difficult adjustment lacked a mutually constructed meaning for the experience and were also struggling with an accumulation of stressors and demands.	Participant constituted a self-selected, homogeneous, well-functioning sample that may have resulted in skewed findings.

Study, Location	Purpose, Population & Health Context	Study design & Sampling	Sample size (n) & characteristics	Main findings	Main limitations
Breast Ca – newly diagnosed					
Sutherland 2009 [301]; Canada	To explore the meaning of being in transition to end-of-life care. Female partners of spouses with cancer receiving palliative care services. Mixed Ca types – palliative care	Cross-sectional, exploratory, qualitative Criterion (purposeful)	n=8 Age: 50-71 y; Duration of relationship: 6 25+ y, 1 16-20 y, 1 <5 y. Patient type of Ca: 3 Colorectal, 2 Lung, 1 Pancreatic, 1 Gliosarcoma, 1 Not stated	Findings centred on three major concepts: meaning-making, anticipatory mourning, and hope. Three major themes outlined the female partners' experiences: 'meaning of our lives' (our relationship, significance of his life, searching for understanding); 'dying with Ca' (burden of caring, uncertain path, looking for hope); 'glimpses of the future' (facing tomorrow, capacity to survive).	Representativeness of the sample may have been limited.
Willyard et al. 2008 [290]; USA	To examine sibling relationships, negotiation of division of tasks, and making sense of sibling responsibility within the caregiving context. Primary family caregivers of at least one elderly parent. Aging/frailty.	Cross-sectional, exploratory, qualitative Part of a larger interview project Convenience	n=25 Age 42-65 y; 23 Females; Duration of caregiving: 2- 'many' y; Daily duration of involvement: 'at least several hours'.	There was little negotiation of caregiving tasks between siblings. Caregivers make sense of sibling participation in caregiving in three ways: siblings especially suited for caregiving; non-participating siblings excused as outside family boundaries; no making sense of sibling non-participation but verbal backtracking to make sense of own participation.	Sample representativeness may have been limited.
Wong and Ussher 2009 [302], Wong et al. 2009 [303]; Australia	To explore the positive meanings constructed and ascribed to the experience of providing palliative care at home. Bereaved primary informal caregivers of patients with Ca. Mixed Ca types – bereavement.	Cross-sectional, exploratory, qualitative Part of a larger study Convenience	n=23 Median age: 57 (19-85) y; 18 Females; 10 Employed; 21 Family members (14 partners); Duration of caregiving: 3 m-57 y	Positive and beneficial/rewarding aspects of caring were identified: discovery of personal strength, deepening of the relationship with the ill person, and personal growth through altered relationships and altered perspectives on living. Being present at the point of death was rewarding because it facilitated the process of saying goodbye and provided closure.	Self-selected sample that may have resulted in skewed findings. Whether benefit construal was achieved as a way of making sense of caregiving and loss could not be determined.
Notes: Ca – Cancer; y – Years; m – Months; CT – Chemotherapy; AML – Acute myeloid leukaemia; NHL – Non-Hodgkin lymphoma; ALS – Amyotrophic lateral sclerosis; AD – Alzheimer's disease; MS – Multiple sclerosis; MI – Myocardial infarction; AIDS/HIV – Acquired immunodeficiency syndrome/Human immunodeficiency virus infection.					

Caregiver meaning-making in non-cancer contexts

In the group of studies identified in various non-cancer contexts, seven studies specifically addressed meaning-making processes of family caregivers, whereas only two explored the end product of this, that is to say, any meanings made [11]. Irrespective of chronic illness, family caregivers seemed to engage in a process to reconstruct meaning through making sense of their self-identity [290, 292], their relationship with the ill person [291, 292] and the extended family [290], or the importance of their caregiving role [290, 291]. Ayres [295] also identified three distinct elements in the meaning-making process of caregivers that included expectations derived from previous experiences, explanations based on personal worldviews, and strategies to manage the current situation. In this endeavour, caregivers may perceive their role either in solitude or in conjunction with other family members [290]. For other family members, benefit- and meaning-finding may be facilitated by deliberate attempts to make sense of and recognise positive aspects in the illness of their loved one [294]. What the impact of this conscious or sub-conscious process is on caregivers is yet to be revealed. Yet, two studies on caregivers of patients with neurological conditions provided evidence on greater psychological adjustment in those carers who also reported greater benefit-finding [293] and on various attributes that may aid making sense and facilitate psychological adjustment [217]. Although not exhaustive, this list of factors might include the carers' perception of their situation as a catalyst for change, as something to be simply accepted, as incomprehensible, or as an expression of closeness in relationships [217], thus proposing a range of more active or more passive approaches to their lived experience. The end product, that is the meanings made, might come in the form of different stories depending on the perceived positive or negative effects of the illness on the carers' lives, both at an individualistic level and through the shared experiences in the wider family context [296]. In that sense, feelings of family closeness and a sense of purpose and self-worth together with feelings of guilt and a sense of loss of continuity might co-exist in family members' stories of caregiving for their loved ones [289]. Such positive and/or negative attributions may fluctuate according to type or phase of illness, caregiver socio-demographic or personality characteristics, or global meaning, and additional research will be needed to clarify their respective roles.

Caregiver meaning-making in the cancer context

In the context of cancer care, two studies investigated the meaning-making processes of family caregivers in different phases in the illness trajectory [298, 301]; however, the majority of research (five studies) concentrated on determining the meanings made by the carers along the continuum of the cancer experience. Still, substantial variations in the phase of illness, where carers were approached, should deter from any attempt to draw general conclusions. For instance, in the palliative care setting, female carers of spouses with cancer went through a meaning-making process that was initiated prior to the patient's death and included negotiation of several aspects such as finding meaning in their shared lives, dealing with uncertainty instilled from dying with cancer, but also trying to 'glimpse the future' and face tomorrow [301]. When Wong et al. [302, 303] then explored the meanings gained by bereaved family carers, a sense of reward and satisfaction was expressed that helped caregivers construct new meanings after the death of their loved one [302, 303]. Benefit-finding from their experience involved discovering unknown inner strengths, strengthened relationships and a sense of personal growth [302, 303]. Whether such attributes assimilate meanings made in similar caregiving populations is unknown, but should be viewed with caution as this self-selected sample of successfully adjusted family members has created skewed datasets that may not be easily transferable to other caregiving situations. Nevertheless, in a significantly different context, not only did young adults make sense of the cancer diagnosis of their parents through its impact on daily life or as a sense of loss and fear of death, but also through the potential for enhanced relationship closeness [297], thus to a certain extent corroborating the views of carers in the Wong et al. [302, 303] study. In that sense, the fact that only limited evidence exists in support of the idea of dyadic meaning-making can be seen as a clear sign for more research into how patients and caregivers appraise and construct meaning through their close caring relationship. For patients and carers living in a close relationship, attachment systems may operate to maintain security in times of threat. In this process, attachment security expressed as a sense of closeness and easy reliance on others was found to facilitate caregivers' quest for benefit in their indirect cancer experience [298]. Along these lines, Skerrett [299] pointed out that the ability of a couple to construct a shared meaning of illness – breast cancer in this instance – may have influenced their functioning both separately and jointly. In addition, couples who failed to reach mutually constructed meanings, also experienced more problematic adjustment [299]. Even from an individualistic perspective, however, a link between meanings made and caregiver psychological adaptation and adjustment was proposed in two studies, where positive meaning was predictive of better caregiver adjustment to cancer [108], and inability on the partners part to find meaning in the patient's cancer was related to greater cancer-specific distress [300].

Despite a seemingly different focus of caregiving research conducted in various non-cancer contexts (i.e. sense-making process) compared to that taken place in the cancer context (i.e. the end product of the sense-making process), similarities do exist. Indeed, irrespective of context, in their efforts to make sense of their experience, caregivers may rely upon their past experiences and worldviews. The end product of this search for meaning may be directed by different factors, but the closeness of their relationship with the patient seems to be the most common one. Yet, research in the field remains limited to draw safe conclusions on other factors that may play a part in the meaning-making of caregivers (e.g. sociodemographic characteristics) or how meaning may affect psychological adaptation to illness.

2.5 Appraisal of the current literature

Research on patient meaning-making in the context of cancer has focussed on several aspects of Park and Folkman's meaning-making model [11, 14]; however, some components did receive more attention than others. Aspects of the process of meaning-making were invariably investigated to include perspectives of patients with different cancer diagnoses and in different stages along the cancer trajectory (i.e. newly diagnosed, advanced stage, or combinations). As discussed in Section 2.2, the whole process of meaning-making may differ according to the stage of illness and, even more, to the type of cancer, due to the different treatment trajectories. Despite this being a reasonable argument, current available data – limited in amount and quality – fall short to provide concrete evidence on this particular area. Even in the case of breast cancer that has received the greatest part of attention, research has been too diverse to allow for conclusive evidence to emerge. Therefore, future research could usefully focus not only on specific types of cancer, but also on particular periods and components of the meaning-making model to clarify how different groups of patients may make sense of their unique experiences. Furthermore, research regarding global meaning has not expanded yet, perhaps due to the inherent conceptual and practical difficulties in measuring/exploring the concept. For instance, the current review identified predominantly quantitative studies (with the exception of one qualitative study) that measured aspects of global meaning only in a cross-sectional manner, which prevents any inferences from being made with regard to how global meaning transforms over time, or what the magnitude of change in situational meaning related to cancer – and therefore how extensive the discrepancy between global and situational meaning – should be to enable reconstructions in global

meaning overall. In that sense, it would be worthwhile to qualitatively and longitudinally explore how global meaning is constructed and what it entails. Yet, as part of the global meaning of patients with cancer, meaning in life or existential meaning did receive some attention, but in studies employing cross-sectional quantitative methodologies only. Arguably, the lack of clearly defined conceptual definitions of such outcomes as well as the absence of longitudinal designs poses difficulties in deciphering whether these truly reflect aspects of global meaning (as hypothesised in the present review) or perhaps refer to meanings made (i.e. changed meaning in life) along the cancer trajectory.

Despite a notable increase in caregiving research in the past 15 years, evidence regarding the concept of meaning-making of caregivers of patients with cancer remains scant. Researchers employed primarily cross-sectional designs in the studies identified, which implies that when and/or how changes in the different components of making sense take place across time remains unclear. Furthermore, although certain aspects of caregiving such as duration and level of involvement in care-giving may impact on meaning-making processes, these were not addressed in the studies reviewed. Along these lines, factors such as personality characteristics were not considered for their influential effects on either the process or the type of meanings made. There was also a notable absence of studies examining global meaning, suggesting that this area is offered for further research in the years to come. Irrespective of context, research has focussed on the relationship of situational meaning and/or meanings made with caregiver adjustment. However, the concept of benefit-finding from the caregiving experience was only partially touched upon [302-304], particularly the specific aspects of meaning that it may affect. Additional aspects not yet considered include whether meaning-making of family members changes according to the specific family role (child, spouse, or parent), and whether meaning-making can impact on the carers' health status, for example their mental health. Finally, an area that is worth exploring refers to whether meaning-making constitutes a co-constructed endeavour between patients and caregivers that embedded in their close caring relationship, and whether this dyadic meaning-making is dependent on the type and/or quality of the relationship. As previously stated, the limited existing evidence on dyadic meaning-making shows that this area warrants more research.

2.6 Chapter summary

This Chapter has provided an overview of the literature regarding the concept of meaning and making sense with particular focus on patients diagnosed with cancer. Similarly, the literature on the making-sense processes of the family members was discussed providing evidence from the context of cancer and other chronic illnesses. Despite the recent advances in research in the area of meaning-making, there are still issues that merit further exploration and clarification. As Park [11] concludes in her recent review: “rather than asking whether meaning making is helpful in adjusting to highly stressful events, we first need to better understand what meaning making is” (p. 293).

CHAPTER 3 – Selecting a methodology

3.1. Research problem

Thus far, from Chapter 1 it can be gleaned that there is a gap in the literature regarding studies focussing specifically on experiential accounts of patients with acute leukaemia. Furthermore, very limited evidence exists on the experiences of family caregivers in this population. Also, Chapter 2 has placed an emphasis on the process of making sense in the wider cancer context from the perspectives of patients and carers. Again, the dearth of evidence on patients and their family caregivers regarding how they make sense of an illness such as acute leukaemia was noticeable. In order to move towards the development of interventions for people affected by acute leukaemia it is necessary to establish how they make sense of the illness. To this aim, an exploratory design was adopted as it was deemed to be a more suitable one.

The literature confirmed the paucity of research conducted specifically with people affected by acute leukaemia (not as part of a wider haematological population). To tackle how individuals construct their understandings of acute leukaemia, one has to explore their personal experiences of illness. The lack of validated tools for gathering this information within this population dictates the necessity for exploratory research with an in-depth focus on experiences before moving on to the development of measures or interventions specific to the population. Hence, the use of quantitative methodology was rejected due to its inability to provide in-depth information on individual experiences specifically related to acute leukaemia. For these reasons it was deemed necessary to examine the opportunities offered by qualitative methodological approaches to address the aim of this PhD study: how people make sense of acute leukaemia.

The purpose of this chapter is to a) present the ontological and epistemological underpinnings of this study, b) give an overview of the different methodological approaches that could have been used to answer this study's research questions, c) provide reasoning for selecting phenomenology, and particularly, Interpretative Phenomenological Analysis (IPA) over the previously described methodologies, and finally, d) present the selected methodology in detail.

3.2. Research paradigms and philosophy of science

Before moving to the various different methodological approaches it is important to provide some definitions of the terminology used in this section: *philosophy of science*, *methodology*, *paradigm*, *epistemology*, *ontology*, and *axiology*. Following these descriptions, a brief presentation of the main research paradigms is provided with specific focus on the theory of critical realism which is the research paradigm that guided this PhD study.

According to Ponterotto [305], *philosophy of science* refers to the conceptual grounds where the ‘quest for knowledge’ is rooted. Within philosophy of science, there are embedded preconceptions for ontological, epistemological, axiological and methodological underpinnings of the research process [305]. A *paradigm* is defined as a “set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organised study of the world” (p. 34) [306]. Researchers are called to position themselves within a paradigm that will guide their decisions, data handling and the entire research project overall. *Methodology* includes the process of research and the specific procedures or ‘methods’ of conducting research [305]. Despite some contradicting views [307, 308], usually the chosen methodology for a research project should arise from researchers’ ontological, epistemological and axiological standpoints. *Ontology* is the philosophical study of the nature of being, existence or reality [305]. In other words, ontology is about how the world is, objectively, and deals with questions like: What is reality? What are the different entities in this reality and how can these be interconnected? *Epistemology* is the branch of philosophy concerned with the nature of knowledge. It refers to the relationship between the researcher and the truth, ‘the knower (research participant) and the would-be knower (researcher)’ [305, 309]. According to Bhaskar [310], there is a distinction between how the world is (ontology) and the researcher’s perception of the world (epistemology). *Axiology* refers to the set of beliefs and values (‘axioms’) researchers bring to the research process [305]. Depending on the research paradigm, the researchers will bring in different levels of axiology [305].

After providing the definitions of the terminology used, three paradigms are presented, positivism, constructivism, and critical realism, detailing their epistemology, ontology and axiology. *Positivism* is a paradigm that aims to verify or reject predefined hypotheses. It presumes that the natural and the social world can be examined by using the same hypothetico-deductive (theory testing) methods [305, 311-313]. These methods involve the close observation and description of phenomena that exist as part of theoretical models; the formulation of hypotheses which are then tested through experiments and statistical analyses and eventually accepted or rejected [305]. The epistemology of positivism is characterised by

dualism and objectivity [305, 313]. The researcher and the subject of research exist independently from one another and neither can influence one another [305]. The knowledge can be obtained through rigorous, standardised free-of-bias procedures [305]. Positivism is ontologically underpinned by naïve realism: the notion that there is a single reality that can be objectively measured [314]. Interestingly, later authors have argued that naïve realism in fact counteracts logical positivism [311, 315]. In terms of its axiological stance, researchers have no influence on the research process; conversely, their efforts are focussed on remaining detached from the research process, separating science from personal experience. This paradigm, however, has certain weaknesses with regard to understanding social structures and uncovering meanings of the phenomena under investigation, and relies on a linear, often inflexible, design (which makes adaptations to a later stage of the research process not feasible). For these reasons, positivism has been rejected as a philosophical stance for this PhD study.

Constructivism lies at the opposite side of the spectrum from positivism. It has also been referred to as *interpretivism* [305, 312-314]. Constructivism adheres to a subjectivist epistemology; the world exists only in conjunction with our knowledge of it [305, 313]. Here, the fundamental aspect is for the researcher to create a close relationship with the individual in order for the 'lived experiences' and meanings to be constructed and expressed [305, 312]. Ontologically it is underpinned by relativism, according to which there are multiple realities, as many as there are individuals [305, 312-314]. Knowledge and reality are 'constructed' from the human interaction with the social world and develop and exist within a social context [313, 316]. Constructivists use a hermeneutical approach to uncover the hidden meanings of phenomena under study via reflexion [305, 317]. The dialectic between the researcher and the object of research is considered to be the crucial element in discovering meanings and comprises the major difference with positivism [305, 317]. Therefore, its axiology supports the idea that the personal values and experiences of the researcher cannot be dissected from the research investigation [305, 312]. On the contrary, they should be fully acknowledged and 'bracketed' but never discarded [305, 312, 317]. Constructivism is rejected as a philosophical stance for this PhD study due to its ontological stance of the non-existence of a single reality, an idea which tends to lean towards solipsism¹ [318]. As Pawson and Tilley [318] argue, positivism is accused of 'context-stripping' and constructivism of 'context-hopping' (p. 23).

¹ Solipsism is the philosophical idea that only one's own mind can exist.

Positivism and constructivism comprise only the two extremes in the continuum of research paradigms. Between these two there are other more middle-ranging approaches, some closer to the former (post-positivism), others closer to the latter (social constructionism). Of these, *critical realism* was selected as a better fit to the professional background of the researcher, to underpin this PhD study. The basic tenets of critical realism are further presented here.

Influenced by the philosophy of Kant, critical realism seeks a cause, a pattern in events, that is concerned with the question ‘what causes things to happen in certain ways?’ [319]. The basic tenets of critical realism were first described by philosopher Roy Bhaskar [310] who criticised positivism for trying to explain phenomena under universal laws and the fact that knowledge could only be obtained through objective observation [310, 320]. He proposed that epistemology should not collide with ontology [310, 320]; in fact, reality is not dependent solely on how individuals perceive it but the causality and tendencies should be of relevance [319]. To explicate this, critical realism, while recognising the contribution of science and accepting the possibility of objective knowledge, also acknowledges the social context within which humans exist. The natural and the social world exist irrespective of human existence [320]. Thus, individuals’ experiences and meanings can still coexist and impact on persons’ behaviours and wider social structures [319, 320]. Critical realists accept that there can be more than one valid explanation of a singular phenomenon [321, 322] and are specifically interested in generative mechanisms of such phenomena [323].

Critical realism offers a middle path that addresses the weaknesses of positivism and constructivism and is:

“ ... committed to ontological realism (that there is a reality, which is differentiated, structured, and layered, and independent of mind), epistemological relativism (that all beliefs are socially produced and hence potentially fallible) and judgemental rationalism (that despite epistemological relativism, it is still possible, in principle, to provide justifiable grounds for preferring one theory over another).” (p. 224) [324]

Critical realism differs from other middle-range paradigms, such as postmodernism in that there is a single truth that is, yet, formed from a set of values, and from relativism in that it does not blindly embrace all ‘instances of difference and diversity’ [323]. Reality in critical realism is structured at three levels: the actual, the real and the empirical [320]. The actual reality refers to events that can be observed; the real refers to the structures, and tendencies that are necessary for the events to occur in the actual level; and the empirical refers to the human experiences and perceptions that are liable to err [320].

The term 'causation' is central in critical realism, however, it neither follows a linear direction nor is it successive [320, 323, 324]. Phenomena occur in the form of patterns as a result of many factors being present in specific contexts under certain circumstances. Therefore, in order to understand these patterns, researchers need to look underneath them [320]. In health promotion in particular, identifying, assessing, enhancing or reducing these causal links that create these patterns is embedded in a critical realist approach [323]. Hence, this philosophical stance was adopted for this PhD study.

3.3. Reflecting on different qualitative methodologies

Selecting a methodology to best answer the research question of this PhD study was a challenging task. An array of different qualitative methods is available; some focussing on description and others focussing on interpretation. The aim of this study was to uncover meaning-making processes when people experience a diagnosis of acute leukaemia, therefore the focus was on interpretation. For this reason, descriptive qualitative methods, such as content analysis [267, 325], thematic analysis [326] either with or without the aid of a framework [327], were deemed inappropriate. Although these methods can provide descriptions of the phenomena under study and are more interpretative than survey data, they qualify as topic or thematic surveys, according to Sandelowski [66, 79, 328, 329]. This means that the findings show little transformation from the actual, raw data in the proposed typology of classifying qualitative findings [79, 330]. Hence, a number of interpretive methodological approaches were considered when designing this PhD study. Ethnography, grounded theory, case study, discourse analysis, and narrative analysis were examined and eventually rejected for different reasons; these are presented in the next section.

Ethnography

The word 'ethnography' is derived from the Greek noun *ἔθνος* (*ethnos*) which means 'nation', and the verb *γράφω* (*grafo*) which means 'write'. Ethnographic research focuses on detailed theoretical descriptions of the cultural impact on small groups or societies [331]. It is rooted in the works of cultural anthropologists and their work on cultural comparisons [332]. Ethnographic researchers primarily use field observations in order to immerse themselves in

the trivial lives of the participants sharing a culture/context in order to describe behaviours and language [321, 333]. Hammersley and Atkinson [333] provided a way to conduct ethnographic research by emphasising the importance of gatekeepers, the reciprocity of the researcher between the researcher and the subjects under study, and the possible impact of the researcher on the research process (reactivity). Usually, fieldwork requires the researchers to spend prolonged time with the group under study. Hammersley [331] suggested subtle realism to guide his ethnographic research and lately other researchers have conducted ethnographic research underpinned by a critical realism approach [319, 334].

Ethnography was rejected as a methodology for this study on the grounds of time restrictions set by the course of the PhD study duration; and due to the fact that the aim of this study focussed on meaning-making processes and not the influence of culture on persons' meanings.

Grounded Theory

Grounded theory has received great attention, especially in health research, since it was first described by Glaser and Strauss in 1967 [335]. They developed the method out of their need to cover existing gaps in prevailing theories of sociological research. Their aim was to create a method and a methodology that would offer new theories that would be 'grounded' in contextual data [309]. To achieve this goal they provided a rigorous step-by-step process of coding data (grounded theory as a method) that would result in the *discovery* of a new theory (grounded theory as an end product), an element which is often absent from other qualitative methodologies. Key techniques utilised in this theory are constant comparative method, theoretical sampling and theoretical saturation. They adopted a pragmatic approach that did not lack logic or systematic procedure of quantitative methods [309]. This is one of the main reasons that Grounded Theory is seen as one of the most rigorous ways to conduct qualitative research.

Since its inception, Grounded Theory, like other methodologies, has been revised significantly [336]. Its founders have offered two different ways to conduct the method: Glaser [337], Strauss and Corbin [338]. In 1990, Kathy Charmaz proposed a third version of Grounded Theory from a social constructionist perspective [336, 339]. Its underlying difference with the former two versions lies in the fact that the theory is not discovered; that is to say, it already exists and the research process uncovers it. The theory is seen to be a constructed product of the research process between the researcher and the data. In her version, Charmaz addresses issues of reflexivity that other versions have failed to incorporate [336, 339].

Given that the purpose of this study was not to provide a new theory of how individuals create meaning of acute leukaemia, but rather to offer an in-depth exploration of their sense-making processes, Grounded Theory was rejected.

Case study

Despite the fact that some methodologists do not consider case study to be a distinct research method, it merits mentioning in this section. Case study is suggested to be an approach rather than a method, of conducting qualitative research with its focus being the *case* [340]. A variety of different methods of data collection and analysis can be used [309, 332]. The case can involve either one single participant/site or multiple individuals/sites [332]. A case study has certain characteristics: an idiographic focus, the focus on specific context, triangulation of data (data collection from multiple sources of information), the significance of time (how things are processed over time) and possible generation of a new theory [309, 332].

Although the case study lends itself as an appropriate method of uncovering making-sense processes, the issue of data triangulation seemed to be restrictive in terms of time, due to having to solely target patients and family carers. The researcher invested her efforts in exploring meaning-making processes in a broader sense rather than comparing processes across different individuals within one case, hence the case study approach was rejected.

Discourse Analysis

Discourse Analysis is a methodology used predominantly by psychologists in order to uncover meanings and constructions of social reality conveyed by language. There are two types of the discourse analytic method: *Discursive psychology* and *Foucauldian discourse analysis*. Discursive psychology challenges cognitivism and was introduced by Potter and Wetherell [341]. Foucauldian discourse analysis was influenced by the post-structuralist, Foucault [309]. Despite the view that these two methods can be used complementarily, Willig [309] proposes that they are used to answer different types of research questions. On one hand, Discursive psychology is concerned with how persons make use of the language in order to deal with their social environment and 'achieve interpersonal objectives' (p. 91) [309]. On the other hand, Foucauldian discourse analysis is concerned with the description of persons' discursive worlds and the exploration and theorising of their experiences [309].

The interest of this project was to uncover meaning-making processes of individuals affected by acute leukaemia and not the power of language to create such processes. For this reason, both types of discourse analysis were rejected as a methodology for this PhD study.

Narrative inquiry

Narrative analysis focusses on the meanings created through the telling of a story; a narrative. The researcher asks the participants to share their experiences through storytelling, the produced narratives are then analysed within each individual case and then across the group and finally, are re-told by the researcher [342]. Narrative analysis may differ from other forms of qualitative research in the dynamic between the researcher and the participant (story-teller); the participant is in control of the story that is told and creates the links between the end product and the researcher's understandings and interpretations [343]. The work of French philosopher Paul Ricoeur has been influential; in fact, he proposed that the underlying relationship between human existence and time is expressed through the narrative [343, 344]. Some authors have criticised the use of the term 'narrative' to be equal to the term 'story':

"... 'Narrative' is the rehearsal of a sequence of events, causally connected. [...] 'Story' is a specific form of narrative which takes the causal sequence of events, and organises it in such a way as to construct a plot, with a central character, a problem, an explanation and an intended reaction" (p. 89) [345]

Holloway and Freshwater [343] argue that narrative inquiry has received increasing interest from nurse researchers over the last decade. A variety of different approaches have been attributed to narrative analysis, such as thematic, structural, interactional or performative analysis [346].

The focus of this study was to identify and explore the different facets of the making-sense processes that patients and family caregivers would find important within the experience of acute leukaemia and not to compose a causally coherent sequence of events in the meaning-making process. Because sense-making may or may not be coherent, sequential or causally linked, but contradictory and non-linear, narrative inquiry was rejected as a theoretical model for this study.

To summarise, different methodological approaches were examined for their suitability to answer the research questions set for this PhD study. Ethnography, Grounded Theory, Case study, Discourse analysis and Narrative inquiry, all were rejected for different reasons. The opportunities for the exploration of meaning offered by phenomenology are presented in Section 3.4, and the reasons for selecting a particular type of phenomenology are also visited.

3.4. A methodology of making sense of illness

The word ‘phenomenology’ is derived from the Greek words ‘φαίνω’ (*faino*) that means ‘appear, present’ and ‘λόγος’ (*logos*) that means ‘talk, articulate’. It started as a strand of philosophy a century ago, and its focus is on how persons obtain knowledge of their world around them and create meaning about certain phenomena. The selected methodology that guided this PhD study was a particular type of operationalised phenomenology. This section briefly presents the philosophical origins of phenomenology as a research approach.

3.4.1. Phenomenology as a ‘radical way of doing philosophy’

According to Moran [347], the primary focus of phenomenology is a different ‘radical way of doing philosophy’. The father of phenomenology was Edmund Husserl, a mathematician who was influenced by the work of Brentano [347]. In Husserl’s ground breaking work, *Logical investigations*, he suggested that philosophy can be practiced rigorously in a similar way to science [348]. Therefore, according to Husserl, through the ‘phenomenological method’, the experienter could arrive at an objective truth of a specific phenomenon which he then could describe in detail in the manner it appeared or presented and he became conscious of [347, 349, 350]. In this sense, phenomenology is first and foremost concerned with *eidetic reduction*, which involves setting aside all previous preconceptions of the experienter, to *bracket* himself, through suspending the natural attitude. The natural attitude assumes that objects pre-exist persons’ attention [349]. This presupposition of human awareness of the existence of natural objects is called ‘intentionality’ [350]. The aim is to move from ‘naïve understanding of the object to the object itself’ through intuition as it presents consciousness genuinely [349, 350]. Husserl wanted to grasp the essence that makes possible an experience of any kind.

The German philosopher, Martin Heidegger, Husserl's student, took phenomenology a step further. In his seminal work, *Being and Time*, he has set the grounds for a different philosophical thinking [351]. Indeed, he discarded some of the major notions of Husserl's phenomenology. He criticised and rejected the idea of intentionality and introduced the idea of *Dasein* which literally means 'there-being' [347, 350, 352]. According to Moran [347], *Dasein* cannot 'stand on its own'; it is an entity that pre-exists and co-exists with the world, the environment. A close concept to *Dasein* is *Mitsein* which means 'being-with'; humans exist with their world, they are not thrown into the world but their understandings and experiences are forged by their relationship with the world [352]. Heidegger also introduced ideas such as *intersubjectivity* and *temporality*. Intersubjectivity refers to the idea that humans' engagement with the natural world is always interlinked in a relational manner and aims to interpret humans' ability to communicate and make sense of one another [352]. 'Temporality' refers to the idea of 'all possibilities of being or existence' (p. 288) [350].

Phenomenology, for both Husserl and Heidegger, focusses on examining something that may be hidden; as it becomes apparent, it emerges. However, for Heidegger, phenomenology is also concerned with examining both the object that becomes evident and its relationship with its previous underlying nature [352]. Heidegger also reintroduced the idea of the hermeneutic circle from Schleiermacher, hence he is considered to be the father of hermeneutics [350, 352]. As he rejected the idea of bracketing and reduction – meaning is always created through some extent of pre-assumptions – he proposed the hermeneutic circle where there is a dynamic influence between understanding and pre-understanding [347, 350, 352].

Hans-Georg Gadamer, another German philosopher influenced by the work of Heidegger, has added two more concepts into phenomenological philosophy: *prejudgement* and *universality* [347, 350]. In his work, *Truth and Method*, he explains that prejudgement refers to the set of prejudices people possess and that universality is a connection between people's expressions and people's understandings [347, 350]. He also emphasised the role of language in the 'understanding of being in the world' [347] and that, in fact, language will always be biased due to its pre-existing cultural influences [350].

Phenomenology further evolved by the works of French philosophers Jean-Paul Sartre and Maurice Merleau-Ponty. Sartre extended certain aspects of existential phenomenology. He introduced the idea of *nothingness*, highlighting the equal importance of the absence of things with those that are present in facilitating people's understanding of the world [352]. He expanded Heidegger's view of worldliness of human experience by adding the significance of contextualised human relationships [352].

Finally, Merleau-Ponty in his work, *Phenomenology of perception*, focusses on description rather than interpretation [353]. He postulates that the ultimate goal of phenomenology is to grasp the 'primacy of perception' [350, 354]. He differentiated between the body-object (physical biological aspects) and the body-subject (experiential aspect), stating that persons' knowledge and understanding of the world comes from the embodied nature of their relationship with the world – this is what he called *embodiment* [352, 354, 355].

3.4.2. Phenomenology as a research approach

All the philosophers presented in section 3.4.1 have contributed to what constitutes phenomenology as a philosophical approach. Phenomenology, however, has also been used as a way to conduct research in several different disciplines, nursing being among them. The predicament that has arisen originates from the discrepancy between phenomenology as philosophy and phenomenology as a research approach [356-359]. None of these philosophers proposed a 'how-to' conduct phenomenology as a method of doing research [349]. Therefore, some of the basic concepts were misinterpreted, specifically in nursing, resulting in a 'new era phenomenology' or rather the 'study of lived experience' [316, 350, 359]. Later on, academics, such as van Mannen and psychologists, such as Giorgi, suggested different ways of how to conduct phenomenology in research. In this sense they made phenomenology more approachable for researchers. The Giorgi [360], Colaizzi [361] and van Manen [362] approaches are presented here, as these philosophies have had the greatest impact on nursing research.

The Giorgi approach

Amedo Giorgi is one of the few psychologists (along with Johnathan Smith) who, after proposing a method to conduct phenomenological research, continues writing and expanding on the field [360, 363, 364]. His method includes four steps. Firstly, the account is read in order to get a sense of the whole. Secondly, the researcher tries to find 'meaning units', or the parts of the description. Thirdly, questions are asked that are relevant to the study's aims, in order to form themes. Finally, in the fourth step there is an attempt to bring together the essential themes with the non-redundant themes.

The Colaizzi approach

Colaizzi's method is the most commonly used phenomenological method in nursing [365]. Thomas [354] has been critical with this 'prolonged allegiance' as she could not find any evidence that Colaizzi continued working on developing his approach to phenomenology. Colaizzi's [361] method involves seven steps, again starting with reading and re-reading the account to get a sense of the whole. Then, significant statements relevant to the phenomenon under study are extracted. The next two steps concentrate on the formulation of meaning from the statements, and subsequently, these are classified into categories, clusters of themes and themes. In the fifth step, the findings are integrated into an 'exhaustive description' of the phenomenon under study, and afterwards the structure of the phenomenon is detailed. Finally, validation of the findings is sought from the research participants by asking how these descriptions related to their experiences.

The van Manen approach

In his work, van Manen draws on the links between phenomenology and hermeneutics [362]. His approach focuses on the examination of everyday practice on pedagogy and parenting [362]. His method involves reading and re-reading the account in order to grasp the fundamental meaning of the account; this he called 'holistic reading approach' [365]. In this way essential themes are created. Then, the 'selective reading approach' follows where the essential themes are reflected by their variations [362].

There are a number of different issues within the various different approaches to phenomenology that merit attention. Pringle [366] has summarised the four areas where scholars are in debate: i) the focus on either description or interpretation, ii) bracketing, iii) the insider – outsider perspective, and iv) reflexivity. Firstly, there is a conflict on whether phenomenology is descriptive or interpretative. Some argue that phenomenology in its core is purely descriptive [367], while others have suggested that all phenomenological descriptions are, to a certain extent, interpretative [362]. According to Pringle [366], 'phenomenology' is focussed on uncovering meanings whereas 'hermeneutics' is concerned with interpreting these meanings. Secondly, the extent to which researchers can bracket their previous assumptions has been largely debated [366]. Crotty [349] and Paley [357, 358] supported the notion that bracketing is impossible to achieve; others suggested bracketing is a way to retain

researcher's objectivity [368]. Pringle [366] concludes by stressing the importance of transparency on a research project by supporting the findings with participants' quotations. Thirdly, whether a researcher is an insider or an outsider has been said to influence the research process. The insider perspective, that is, when the researcher has some relevant knowledge of the study area, has the potential to approach study participants more empathically. However, this perspective can also create the problem of pre-assumptions not being explicitly explained [366]. In order to adopt a more outsider perspective, methods such as keeping reflexive accounts, outsider verification and member checking, have been proposed [366]. The issue again is whether it is possible for researchers to have an outsider perspective in the research process, when normally, before setting out for interviews, other steps have already taken place (i.e. reviewing relevant literature for funding proposals or ethics applications) [366]. Finally, reflexivity refers to the balancing act between acknowledging one's preconceptions and make use of them as a 'source of insight' [369]. Shaw [370], in her recent paper, proposes the use of a continuum to describe reflexivity. She differentiates reflexivity, which involves guiding a researcher's glance back in himself, from reflexion, that aims to 'achieve a positivist goal of accuracy when reporting participants' accounts of reality' [370].

3.5. Interpretative phenomenological analysis

Interpretative phenomenological analysis (IPA) is the most recent version of operationalized phenomenology and was first introduced in 1996 by Smith [371]. The exact steps were then described by Smith and Osborn [372]. Originally, Smith [371] proposed IPA as a different way to conduct qualitative research in health psychology, but within the last decade, other disciplines have adopted IPA, such as counselling, nursing and education [373-375]. Its increasing popularity lies mainly to the – almost – prescriptive nature of the analysis process that makes IPA appealing, particularly to novice researchers [376]. Albeit a detailed process, the danger of misapplying the method remains [373].

IPA was chosen as a good fit for the aims of this PhD study. This section presents its theoretical underpinnings, outlines the steps in the research process, and provides justification for selecting it over other phenomenological approaches reported in section 2.4.2.

3.5.1. Theoretical underpinnings of IPA

IPA is particularly focussed on the examination of how people make sense of important life experiences. As Smith and Larkin suggest, its aim is to tap into people's reflective accounts of what these important life experiences mean to them [352, 376]. This particular focus on meaning was a significant reason for selecting it over other approaches. Smith [352] defined IPA as:

"...an approach to qualitative, experiential and psychological research which has been informed by concepts and debates from three key areas of the philosophy of knowledge: phenomenology, hermeneutics and idiography" (p. 11)

What IPA takes from each of these three areas is presented here.

Phenomenology

IPA shares Husserl's focus on particular examination of the lived experience. However, Smith acknowledges the impossibility of gaining knowledge of the essence of phenomena; IPA only attempts to capture specific experiences that are experienced by particular people [352]. Heidegger's work has also been influential; IPA adopts the view that people always form their understandings of the world through their social interactions. From Merleau-Ponty, IPA takes the notion of embodiment: the body-subject formulates humans' understanding of the world. Finally, the idea that the contextual understanding of experiences is very much dependent on the presence or absence of people's relationships, both interpersonal and social, is adopted from Sartre's viewpoint [377]. Therefore, this engagement with making sense of human experience has an embedded 'lived process, an unfurling of perspectives and meanings, which are unique to a person's embodied and situated relationship to the world' (p. 21) [352]. For this reason, the focus will always be to interpret participants' meanings of their experiences.

Hermeneutics

Heidegger's influence on IPA lies with his view that phenomenology is an intrinsically hermeneutic activity. Gadamer's view that the interpretation is influenced by the specific moment in time when the interpretation is made is also important for IPA. Schleiermacher, whose original work concentrated on the interpretation of historical texts, gave IPA the added

value of the end product receiving input from the sum of the cases as well as the in-depth examination of each one of the cases [352].

A central tenet of hermeneutics is that of the hermeneutic circle: a circular way of perceiving information. There is a dynamic relationship between the part and the whole: in order to understand the part one has to see the whole, and in order to understand the whole one has to examine its specific parts. The hermeneutic circle refers to IPA iterative nature: during the analysis the researcher moves back and forward in order to conceptualise the data and not in a linear fashion where one phase follows the other [352].

Idiography

IPA's focus is on idiographic inquiry, as compared to nomothetic inquiry [352]. This idiographic commitment has a two-level function. On the one hand, IPA aims to examine in detail particular experiences of particular people in particular contexts. On the other hand, from a methodological point of view, the analysis is detailed and very intensive in order to present accounts of a small number of participants [376]. In the end, the statements that are made to represent the whole group can always be traced back to the level of the individual.

Larkin [376] posits that there must always be a balancing act between description and interpretation when conducting an IPA study. The balance of the insider- outsider perspective is necessary. The insider, phenomenological perspective involves the researcher being open to participants' stories and giving priorities to their worldviews, while from the outsider, interpretative perspective, the researcher tries to make sense of the participants' experiences and present them in a way that answers a research question [378]. For Smith [352, 372], in doing IPA research there is a 'double hermeneutic': the researcher making sense of the participant making sense of an experience.

3.5.2. Sampling

Smith [352] suggests that because the focus of IPA is to create fine-grained accounts of specific people in a certain context, the sampling strategy should be focussed on homogeneity to the level this is possible. Apart from aiming for homogeneity, samples should be purposive [352].

Purposive sampling allows researchers to select participants because they can illustrate a feature that is of interest for the study being undertaken [379]. Therefore, it assumes a level of critical thinking of the specific parameters one should choose from a particular population. However, acknowledging the fact that in real life research there are more factors – practical issues, time constraints, population characteristics – potentially taking place, researchers should be pragmatic and more flexible in their inclusion criteria [352].

The sample size of an IPA study is advocated to be small in order to be manageable and to allow necessary depth during the analysis. Hence, for a master's degree, three participants are enough, for a professional doctorate, a sample size of up to ten participants is sufficient, and for a study at PhD level it can vary depending on the type of the research question and the quality of the data obtained [352]. The general suggestion is that 'less is more' in order to retain the idiographic nature of IPA [352, 373, 374, 378, 380]. Although the smaller samples can be considered to be a limitation of IPA studies, they do offer space for richer, more in-depth analysis by providing the opportunity to spend more time on each account. Just as with the issue of homogeneity, space for flexibility should be made as the sample size of an IPA study should be decided based upon the specific context the study is to be conducted in.

3.5.3. Data collection: in-depth interviewing

Smith [352] advocates that the best way to elicit people's meanings is through one-to-one, face-to-face interviews. In order to do a good IPA study one must try to obtain a certain level of richness in the data and for this reason good interviewing skills are necessary to the researchers [375]. Usually researchers use semi-structured interviews that allow them to be better prepared for any possible difficulties and a 'more engaged and attentive listener and a more flexible and responsive interviewer' [352, 373, 378]. However, a more unstructured interview style is considered to elicit even better data due to setting the participant's agenda at the centre of interest [352]. The suggested duration of an interview ranges from 60 to 90 minutes.

An interview should be a discussion that has a specific purpose, or topic. One-to-one interviews are favoured over other types (i.e. focus groups) of interviewing because of their manageability, the fact that it is easier to build rapport, allow for participants to be more open in expressing their thoughts and experiences, and are more suitable for the nature of in-depth, usually personal, matters to be discussed [378]. The interviewer takes on the role of a 'miner'

who, according to Kvale [381], enters the participants' world by asking open-ended questions. Both interviewer and interviewee play an active role; the first by using probes and iterating and the later by offering genuine responses [382].

The optimum number of interviews is another debatable issue. The use of one-off interviews is the most commonly used method of data collection in IPA studies [374]. However, the use of multiple interviews in IPA studies has also been examined. Flowers [383] states that multiple interviews with the same participant has the potential advantage of providing richer data due to the rapport established, as long as the time interval is not going to add serious recall issues. He also proposes that the solution to deal with the later problem of writing the narrative of such accounts could be the combining of interviews and analysing them as one 'mega interview' [383].

3.5.4. Data analysis

As already stated in the beginning of this section, IPA offers an operationalised way to conduct phenomenology, one that is more 'user-friendly' compared, for instance, with the van Mannen method [384]. The analysis proceeds case by case and only after each case has been worked individually does the analyst move to the group level analysis [352]. The six steps of the analysis process are as follows, starting with one case:

1. Familiarising oneself with the transcript by reading and re-reading. In this way the passages with greater detail are located, as well as potential contradictions within the same account.
2. Initial noting. Here the preliminary comments are made in the right-hand margins of the transcript. These comments are descriptive, linguistic, and conceptual. Descriptive comments are used to rephrase issues that were of significance to the participant. Linguistic comments are made when the analyst pays closer attention to the language that was used. Pauses, pronoun use, repetitions, and metaphors are important to note. Conceptual comments can take the form of interrogating the passage, but must always balance between empathy and suspicion [376].
3. Development of emergent themes. On the left-hand side of the transcript, emergent themes are developed based on the previous comments and the actual accounts of participants. In this stage the hermeneutic circle takes place: specific passages are

significant but only in relation to the entire interview and the whole interview is understood from these parts.

4. Looking for connections across emergent themes. Here, points of convergence or divergence across the themes are mapped leading to the development of sub-ordinate themes. Smith [352] mentions strategies such as abstraction, polarization, contextualisation, numeration, and function to aid this process.
5. Moving on to the next case. In doing so, the researchers are encouraged to set aside all themes from the first case, and move on the second participant by starting the process again with fresh eyes. This helps in preserving the idiographic nature of IPA.
6. Looking for patterns across cases. It is only at the end, after each participant's account has been analysed in full, when the researcher looks for similarities and patterns across the group. Here re-labelling of themes can occur. The sub-ordinate themes are further organised in a more abstract level to create superordinate themes.

Researchers are encouraged to move to deeper levels of interpretation by moving away from what is apparent [352, 366, 380]. More recently, Smith [385] highlighted the existence of a 'spectrum of gems' in the analysis process. A gem is something that 'stands out', 'demands attention' and 'prompts further analytic work' in an account [385]. Locating the gems in participants' accounts can aid towards deeper layers of interpretation, thus increasing the quality of a research study.

3.5.5. Rigour

The issue of quality in IPA studies has been examined [373-375]. Smith [352] presents how an IPA study can be assessed for its quality according to Yardley's [386, 387] four principles: i) sensitivity to context, (ii) commitment and rigour, (iii) transparency and coherence, and (iv) impact and importance. These principles are explained below. A detailed description of how these principles are followed in this PhD study is presented in Section 4.7.2.

Sensitivity to context can be demonstrated in a research project through the inclusion of the relevant literature, the consideration and description of the socio-cultural context in which a study is conducted, and through addressing relevant ethical issues. Commitment is shown during data collection process and through in-depth level of analysis. Rigour, which refers to conducting research thoroughly, can be shown by how the sample was selected, and the level of pursuing homogeneity. Coherency is demonstrated by the clarity of the arguments stated throughout the research process (from the literature review, stating research questions and

presentation of findings, to discussion). Transparency refers to the clarity with which the different steps of the research process are described. It is shown in data collection and data presentation. The audit trail, keeping a record of all decisions made in the research process, is necessary for transparent research. Also, researchers' keeping of reflexive accounts is another way for enhancing transparency. Finally, the principle of impact and importance is demonstrated when the findings of a project can influence the wider field of a discipline, or a professional domain.

3.5.6. Contribution to theory

The idiographic nature of IPA was already highlighted in the literature [378, 380, 384]. This commitment to the particular case has both benefits and limitations. This focus of IPA on the individual is regarded as a limitation of the method, compared, for example, with a study using a grounded theory approach. However, the main focus of IPA is not to construct a new theory, but rather it has the potential to inform an existing theory by offering a 'micro-level' analysis of individuals [352]. This is why the idea of saturation does not apply in IPA [374]. Visiting and re-visiting the same account has the potential of resulting in a different interpretation every time as it is dependent on the researcher's contextual experiences.

To counteract this view, focussing on specific people offers researchers the advantage of learning how specific people deal with specific situations in specific contexts in great detail. This detail can reveal links and possibly variations within this same participant of how they make sense of that experience. Moreover, according to Smith [380], this closer look into the particular can lead researchers 'closer to the universal'. He suggests that, instead of thinking in terms of empirical generalizability, researchers should consider the theoretical transferability of an IPA project [352]. Therefore, readers of an IPA study drawing upon literature, personal and professional experience can see how the findings can be transferred to similar contexts or vice versa, not how they can be relevant in other contexts [352, 380].

3.5.7. Methodological considerations

In selecting IPA as a research approach there are further methodological issues to consider. When Smith [372] proposed the six steps of analysis he also stressed the flexibility of the

method. Therefore, contrary to Giorgi's structured approach, he emphasised the non-prescriptive nature of analysis, especially for the more experienced researchers [352, 366].

In terms of analysis, IPA differs somewhat from other phenomenological approaches as it focusses on interpretation, whereas, for example, Giorgi's approach is focussed on description. Giorgi tried to operationalise Husserl's phenomenological method, while IPA shares links with the wider phenomenological movement. The end product, therefore, for Giorgi would be an account based on similarities among participants, when an IPA account would focus on both similarities and differences in participants accounts [352].

Bracketing researchers' previous ideas can be difficult to achieve, if even possible [388]. As mentioned in section 3.5.6, researchers' previous and current experiences can influence the interpretation of an account at any given time. LeVasseur [388] proposes a way of perceiving bracketing in terms of the hermeneutical circle: by questioning what is already known, the researcher moves on to the next level of interpretation. In this sense every turn in the circle represents 'another stage of pre-understanding' (p. 418) [388]. A way of managing the already perceived ideas concepts is through maintaining an audit trail to enhance the transparency and subsequently ensure the rigour of an IPA research project.

3.5.8. IPA in the context of health research and nursing

The popularity of IPA has increased during the last ten years and will continue to gain ground due to its applicability in different settings [373, 374, 384]. In the context of health research it has been used in studies focussing on illness experience from both patients' and carers' viewpoints [375].

As IPA was initially proposed as a different path between the prevailing quantitative paradigm in psychology and discursive psychology [371], it could be postulated that there may be issues around whether it can be applicable in different disciplines. However, Smith [375], thanks to the flexibility of the method, encourages its use in other fields. Pringle [389] has recently conducted an IPA study for patients recovering from stroke and their family members. Similar IPA studies have been conducted in a cancer context [390-399]. Its focus on the individual is relevant to the idea of holism in nursing and has great potential to be used in nursing phenomenological research [384].

3.6. Chapter summary

To summarise, different epistemological and ontological stances were presented, and critical realism was identified as the most relevant theoretical model to underpin the current PhD study. Also, a range of different qualitative methodological approaches were presented that could have been used to answer the research questions of this PhD study and justification was provided for choosing phenomenology, IPA in particular.

This study exploring the meaning-making processes of individuals affected by acute leukaemia was conducted from a critical realist perspective and utilised IPA as a methodology, thereby acknowledging the plurality of perspectives and the reflexive voice of the researcher.

CHAPTER 4 – Methods

4.1 Study aim and research questions

This PhD study aimed to explore the meaning-making process of individuals – patients and family carers – living with acute leukaemia.

The research questions for this study were:

- How do patients with acute leukaemia make sense of their illness?
- How do family caregivers make sense of the illness of their loved one?

4.2 Study design

The study employed a cross-sectional design utilising serial, qualitative in-depth interviews. The interviews were conducted with people diagnosed with acute leukaemia and their family caregivers to explore their perceptions of illness. Interviews formed the basis for data collection activities.

Participants were contacted on two occasions to provide information on their understandings of acute leukaemia. The first interview was set at any point within the first year of initial diagnosis or relapse of acute leukaemia. The second interview was set between 2 and 4 weeks after the first interview. This interval was considered to be adequate to allow for reflection on what had already been discussed, while being narrow enough for participants to recall issues that arose during the first encounter. In this way the richness and depth of the collected data was secured and also acted as a means of enhancing the iterative nature of this qualitative project [383]. Serial interviewing proved particularly useful for this specific population receiving invasive chemotherapy treatment as a means to reduce possible burden, as the majority of the interviews were conducted during the period of hospitalisation. Issues raised in the first interview could always be revisited during the second for further reflection and clarification.

4.3 Study sites

Participants were recruited from the in-patient and out-patient Haematology Clinics in two clinical sites in Scotland. Permission to recruit eligible patients and family caregivers was granted by consultants in Haematology at each of the two clinical sites.

4.4 Population and Sample

Interviews were conducted with patients who have been diagnosed with acute leukaemia, both lymphoblastic and myeloid, and who were undergoing or had completed anticancer treatment of any stage, during the first year post-diagnosis or post-relapse. A nominated family caregiver – a family member who provides physical and/or psychological support to the patient – was also interviewed.

4.4.1 Sampling strategy

It was proposed that a maximum of ten patients with acute leukaemia in total, along with a maximum of ten family caregivers would be recruited for the study. As already discussed in Section 3.5.2, for a study employing an IPA approach, this sample size should provide sufficient cases for the development of meaningful points of similarity or difference between participants.

Adhering to the IPA approach to data collection, the initial aim was to purposively select participants who met the study's eligibility criteria and who were willing to provide insights on their experiences of acute leukaemia. Nevertheless, because of time constraints and population characteristics (low incidence rates), sampling was instead consecutive and convenient.

4.4.2 Eligibility criteria

The eligibility criteria for participating in the study are listed below:

Inclusion criteria – patients

- Diagnosis of Acute Myeloid Leukaemia or Acute Lymphoblastic Leukaemia (all subtypes included).
- Within one year post-diagnosis but no relapse occurred, or within one year post-relapse.
- Age > 18 years.
- Able to communicate in English.
- Willing to participate in an individual interview with the researcher.
- Able to provide written informed consent.
- No cognitive impairment.

Exclusion criteria – patients

- A diagnosis of any other type of cancer or myelodysplastic syndrome in the past.
- Receiving or having received bone marrow transplantation.
- Receiving or having received pre-treatment chemotherapy for bone marrow transplantation.
- Unable to meet any of the inclusion criteria.

Inclusion criteria – family caregivers

- Family member who provides physical and/or emotional support to a person diagnosed with acute leukaemia.
- Age > 18 years.
- Able to communicate in English.
- Willing to participate in an individual interview with the researcher.
- Able to provide written informed consent.
- No cognitive impairment.

Exclusion criteria – family caregivers

- Unable to meet any of the inclusion criteria.

4.4.3 Recruitment procedure

Working within ethical guidelines, the researcher was not the first point of contact for the patients regarding the study. Hence, the initial approach of potential participants was made by designated local clinicians. Each week local clinicians (a nurse specialist in Haematology and/or a research nurse) helped to identify from the clinic listings potential participants with a diagnosis of acute leukaemia who fitted the study inclusion criteria. While patients were attending the clinic, the local clinicians introduced them to the study by briefly outlining the study and providing them with a study information sheet (see Appendix 4). This process took no longer than 10-15 minutes per patient.

Patients were also asked by the local clinicians to nominate a family caregiver to take part in the study. Nominated caregivers were also approached by the clinicians and handed the appropriate information sheet (see Appendix 4). If the patient or the family member agreed, the clinician flagged the potential participants to the researcher.

The patients and caregivers were given at least 48 hours to discuss whether or not they wished to participate with their family members or the healthcare team. The researcher then arranged an appointment with the potential participant, initially with the patient and later with the caregiver, in order to provide more information about the study and to answer any questions. This process helped in building rapport between the researcher and the potential participants. If the patient and/or the caregiver agreed to take part in the study, the exact location and time of the first interview for both parties was arranged. Following this, the consent form was given to the patient and/or the family caregiver to sign in order to obtain written informed consent for the study records (see Appendix 4).

This process continued until the required number of participants was recruited. All patients and family caregivers who agreed to participate were given an informed consent form to sign; they are considered to be participants in the study thereafter.

The aim of the study was to explore making-sense processes of individuals (patients or family caregivers) and not making sense on a dyadic level. Therefore, it was not necessary that both patient and family caregivers had to participate in order to take part in the study. It was also

decided that, in the case of a patient dying during the course of the study, the caregiver would not continue to take part in the study, because of the arising bereavement issues that were beyond this study's purposes. However, this incident did not occur during the course of the study.

4.4.4 Sample attrition

The researcher was aware that some participants could drop out during this study, as well as that the traceability of participants between interview time-points could be problematic. A number of strategies were employed to maximise retention in the study.

The researcher aimed to maintain contact with patients throughout their involvement in the study in collaboration with the clinical team, in terms of any unexpected developments taking place regarding their physical condition. It was essential for the success of the project within this context for the researcher to establish an effective relationship with the research participants and this was achieved from the moment of verbal consent for participation in the study onwards. It was clearly stated, both in the information sheet and consent forms, that, if a patient dropped out of the study prior to participation in the second interview, their data from the first interview would still be included in the analysis. This, however, did not occur during the study.

4.5 Data collection

Data collection for the study lasted 18 months starting on 1st October, 2010 and ending on 9th March, 2012.

4.5.1 Location of the interviews

The researcher conducted in-depth interviews with patients after recruitment in a place of their choice. This was, in most cases, a private room in the hospital. In one case, after a

patient's request, one of the two interviews took place in the researcher's university facilities in a quiet meeting room.

The researcher also conducted in-depth interviews with family caregivers after their recruitment in a place of their choice. Again, in most cases, this was in a private room in each of the hospital sites, but this was negotiated at the time of recruitment and during contact to arrange the first interview. On three occasions the places of choice for the interviews differed from the hospital setting. One family caregiver selected to be interviewed in her home, while another selected to be interviewed in her place of work, in a quiet room. Finally, one carer chose to be interviewed in a quiet room in the local Maggie's centre. The second interview with this participant was done over the telephone, as the participant had moved to the South of England but still wanted to be involved in the study.

4.5.2 Participant interviews

Interview 1

The purpose of the first interview with patients with acute leukaemia and nominated family caregivers was to explore their perceptions and experiences of facing acute leukaemia. The interviews were designed to capture the range and depth of the participants' experiences, but also allow for sufficient flexibility to enable the interviewer to respond to individual participant circumstances. To this end, interviews started with an open question; 'What does acute leukaemia mean to you?' and then cues from participants' responses would be followed with prompts.

Interview 2

The purpose of this subsequent interview with the participants 2-4 weeks later was to further explore specific issues raised during the first interview. Again, interviews were designed to capture the range and depth of the participants' experiences, were informed by the content of the first interview and allowed for sufficient flexibility to enable the interviewer to respond to individual participant circumstances. The researcher started this interview with a question regarding the intervening time since the last interview (i.e. 'how have the past two weeks been for you?') and then shared a brief summary of the main issues raised during the first interview. This second interview allowed issues to be clarified from the point of view of the participants.

Although both interviews were unstructured and followed the agenda set by the participant, an interview topic guide (see Appendix 4) was devised after the conduction of a pilot interview to test the interview technique (see Section 4.5.3). This topic guide was not prescriptive; instead it was available as a safeguarding technique for the researcher, who was novice in the technique of unstructured interviewing. The topic guide was informed from existing literature, the researcher's personal experience in the field and consultation with the clinical team from one of the two hospital sites.

4.5.3 Piloting the interview technique

This first interview was conducted to pilot the interview technique (data collected were not included in the analysis). The interview was conducted in the hospital, with a patient who had received a diagnosis of acute leukaemia two weeks in advance. Following the guidelines of IPA, the researcher followed an unstructured interview approach, where the interviewer asks one open-ended question and then follows the interviewee's response with minimal probes. However, the reality of conducting an interview differed from the theoretical readings of textbooks. The patients' responses were not as 'rich' as they were 'expected' to be. The fact that the researcher was a novice in this type of interview led to circling around the same issues in hope of getting a 'desired' response, that is, how the patient made sense of acute leukaemia. This issue of not meeting the researcher's expectations created a sense of insecurity that, in the end, was transmitted to the participant as well. After the end of the interview, the researcher, in order to make sure that all areas of interest would be addressed as well as for increasing her confidence, composed a topic guide that was then discussed with academic supervisors and clinical collaborators.

Two lessons were gleaned from the first interview. Firstly, choosing an appropriate time to conduct an interview proved to be an important factor. After consulting with the hospital care team, the ideal time to set the first interview was early afternoon, as there were no clinical procedures planned for that particular patient within that set period of time. However, hospital visiting times should also be considered. Specifically in this case, the interview had to finish early due to the patient's relatives visiting on the day of the interview. Secondly, having 'expectations' or pre-assumptions of people's responses, especially to an experience that has not yet had time to sink in (i.e. acute leukaemia; in that case the diagnosis was made two weeks prior to the interview), should be avoided. This issue is further discussed in Section 4.8.

4.6 Ethical considerations

It is appreciated that whilst this study did not present any physical risks to participants, there could be a potential for emotional or sensitive discussions to take place. Talking about and reporting experiences of cancer can potentially be distressing for people affected by cancer [400]. During the study, considerable care was taken to conduct interviews in a sensitive manner, responding to participants' emotional responses and not probing distressing areas unnecessarily. All participants were clearly informed that they have the right to stop an interview or end their participation in the study at any time and no participant was probed unnecessarily regarding sensitive information.

4.6.1 Ethical and R & D approval

The study received ethical approval by the NHS Tayside Research Ethics Committee A. The Research and Development (R&D) Office approval was provided by the NHS Research Scotland Permissions Coordinating Centre. For a copy of the REC approval documentation, see Appendix 4. The study was also provided with trial indemnity by the University of Dundee. For a copy of the form, see Appendix 4.

4.6.2 Potential risks and safeguarding

The researcher recognised that the interviews led to discussions about the illness, treatment and associated experiences of acute leukaemia, which some participants could find distressing. The researcher was alert to any verbal and non-verbal cues from the participants and interviews would terminate if the participant wished and indicated their desire to withdraw from the study at that time. All participation was voluntary and willingness to participate was reconfirmed at each contact point throughout the study. No undue pressure was put on people to participate or remain in the study if they wished to withdraw.

During the recruitment period the researcher worked closely with the Consultants in the Haematology unit, and the members of each clinical team. When participants agreed to participate, the researcher obtained some basic demographic information (gathered from the Case Report Form) and a background overview of their case through consultation with the Healthcare team prior to meeting for the first interview. This process provided an opportunity

for specific issues relevant to each case to be highlighted, as each case was different and encompassed its own set of unique circumstances.

All participants were reminded that they were free to contact their consultant/health professional team both during and after the research project for support if required. In case the incidence arose when participants wished to speak to someone other than the researcher about any element of their involvement in the study, they were provided with details to contact her PhD Supervisors.

A debriefing procedure followed each interview where participants were thanked for their participation in the study. Participants were assured that their responses would remain anonymous in the thesis and in any publications or presentations which arise from this work where direct quotations may be used.

All data gathered were treated confidentially and all transcripts were anonymised and stored securely. Each participant was assigned a pseudonym to ensure that they will not be identifiable in any publications and reports generated from the study.

4.6.3 Informed consent

During the course of the study and especially during the recruitment and consent procedures, the researcher adhered to the four fundamental ethical principles of justice, benevolence, non-malevolence and autonomy [401].

Following initial identification of a potential participant by the clinical team, the Haematology Nurse Specialist or Research Nurse discussed the study with potential participants. Patients and/or family caregivers were given sufficient time (no less than 48 hours) to consider the study, allowing time for discussion with family/friends, and for the participant to ask questions prior to written consent being provided. Then, an appointment was arranged with them in collaboration with the Nurse Specialist to confirm whether or not they wished to participate in the study and to ask any further questions regarding the study. If a participant agreed to participate in the study, arrangements were made on the exact location and time of the first interview. Written consent was obtained prior to the beginning of the first interview. Participants were provided with a copy of this signed consent form to keep; another copy was given to the clinician to add to patients' case notes. The original signed consent form is stored

securely and confidentially at the University of Dundee. Copies of relevant consent forms and information sheets for the participants can be found in Appendix 4.

Patients with acute leukaemia had the choice of whether or not their General Practitioner (GP) would be informed of their participation in the study. A standard letter (see Appendix 4) was sent to the GP of the patient who consented for this notification to be provided.

This study explored patients' and family members' experiences and making-sense processes of acute leukaemia. Extreme care was taken to ensure that the recruitment and consent process protects a study population which could be considered vulnerable by:

1. Ensuring that each individual understood the nature and purpose of the study and consented voluntarily.
2. Ensuring researcher awareness of verbal and non-verbal cues of the participant within the context of wishing to end/stop an interview and flexibility during the interview to each individual's needs.
3. Contacting the individual prior to the follow-up interview to ensure willingness to continue in the study.

However, on-going process consent, whereby consent is continually open to revision and questioning, was also sought at each following interview contact and on an on-going basis throughout the interview process for these participants.

4.6.4 Confidentiality/Anonymity

All data collected throughout this PhD study were treated with confidentiality. No identifiable information was associated with any of the data generated from the study. Pseudonyms were assigned to participants during the data analysis phase to prevent quotes contained in any documentation resulting from this study to be identified by a name. Participants were informed at the start of the first interview of this intention but it was stressed to them that this pseudonym would in no way be associated with their own name and that it would only be used when referring to their experience within the context of the project.

Personal patients' and carers' data recorded on all documentation were also regarded as confidential. Confidentiality was assured, with all data carefully anonymised and

pseudonymised and stored securely in locked cabinets the researcher's office for the duration of the study. Participants will not be identifiable in any publications or reports from the study.

4.6.5 Data handling

The University of Dundee is registered under the Data Protection Act (1998) for the purpose of conducting research and statistical analysis (health).

All data collected, including the case report forms, were stored securely in locked cabinets in the University of Dundee and were available only to the researcher and her Supervisors for data analysis purposes. Interview transcripts were uploaded into a secure password-protected database. Following the completion of data collection, all interview transcripts, digital audio files and demographic data were archived and will be stored securely for 5 years, according to University of Dundee policy.

4.7 Data analysis

The individual interviews were tape-recorded with participants' consent and transcribed verbatim. Although it is suggested that the researchers conducting a study should transcribe the interviews themselves in order to become better familiarised with the data [352], interviews from this study were transcribed by a professional typist. The researcher transcribed the pilot interview, but this proved to be more time-consuming than what was expected as she is not a native English speaker. However, in order to ensure that the professional typist had captured a verbatim account as well as the familiarisation with the data, the transcripts were read while listening to the audio recording a number of times before the actual analysis started. The two interviews were combined and analysed as one mega-interview [383]. The use of computer software to facilitate the data analysis process (i.e. NVivo®) is not advised for novice researchers [352], therefore manual coding, by using traditional methods of pen and paper, was used for the first steps of the analysis process.

For each participant, a separate word document was created. Following the guidance from Smith, Flowers and Larkin [352], a three-column table was created. The emergent themes

were put in the left hand column, the transcripts of both interviews were put in the middle column with line numbering for easier referencing, while the right-hand column was used for all the initial exploratory comments (descriptive, linguistic, conceptual).

The meaning-making model as described in Chapter 2 (section 2.2, p.37) of this thesis was influential during the preliminary stages of analysis when several elements in the accounts were identified as forming situational meaning or aspects of global meaning. During the final steps of the development of the superordinate themes (i.e. the meaning-making processes), the focus was placed specifically on participants accounts and experiences and the researcher's interpretations of them. These then are further considered and discussed in relation to the meaning-making model in Chapter 7 of this thesis.

4.7.1 Interpretative Phenomenological Analysis

The process of analysis was guided by the procedures outlined in Section 3.5.4. The analytic process started with a detailed examination of each case (patient or carer) separately and continued with an examination of similarities and differences across the cases of each group (patients or carers). Authors advise to avoid comparisons between groups in the sake of preserving its idiographic nature, hence, no effort was made to compare patient to carer data [352, 373]. The patient dataset was analysed first.

The following table offers a snapshot of the initial stages of the analysis process of the account of the participant named 'George'. An example of a fully worked transcript is presented in Appendix 5.

Table 4.1. Example of analysis process of George's account

Emergent Themes	Original Transcript	Exploratory Comments
Leukaemia hard to make sense	CP: Eh, oh right, so ... eh the first thing I'd like to ask you is em, what does it mean to have, to ... what does it mean to you to have acute leukaemia?	He doesn't know what it means to have leukaemia.
Surprise diagnosis	P: [sighs] Em ... I don't really know. It's ... as, as, as I said, this is the second time I've, I've got it and the first time eh I was told, I was really, really ill at the time and em, I had no idea it was going to be sort of cancerous or anything, I just thought it was just some really bad bug I had, and em I got a phone call from the hospital, 'cause I had given a blood test and eh the first thing he said was "oh there's unusual white cells in your blood, could you come into hospital?", and as soon as he said that I knew it was sort of ... cancer-related	Taken by surprise. Having no clue. Leukaemia in disguise as infection.
Leukaemia in disguise as infection		A simple blood test leading to a cancer diagnosis.
General knowledge as frame of reference		General knowledge as frame of reference.
Smoking as a cause of leukaemia	CP: Mmm	Smoking related to cancer.
The 'prisoner' – leukaemia as punishment	P: Em, I've been a heavy smoker for 25 years ... 30 years ... and my first thought was ... [claps hands together] - "I've been caught" ...	Sense of guilt. 'I've been caught': suggestive gem
Knowledge as frame of reference	CP: Mmm	Illness perceptions/previous knowledge of cancer.
Self-blame	P: ... you know I, I know the dangers of like smoking, you know smoking's related to sort of disease and I, I'd sort of just initially thought well it's my own fault, you know I, I know the risks, "I've got cancer now", but as it turns out they don't think that leukaemia has got any relation to, to smoking diseases so, but ... it was, it was a bit of a shock. Once, once I, I got in here and I've got a bit better it was really hard to sort of come to terms with. You know a lot of it was, almost like in a dream world, you know it's like "is this really happening?", I'll, I'll just wake up and it's a bad dream, but – no ... but within, I don't know the first couple of weeks em, I just decided well if I'm going to beat this disease, I'm going to have to sort of buck myself up and have a really positive attitude and that's what I did. E-h, and it seemed to have worked through my first treatment	Self-blame They don't think: Does he think it then? Maybe <i>he</i> relates smoking to leukaemia.
Shock of diagnosis		Leukaemia was difficult to accept
Coping efforts		Sense of living in an unreal world.
Dream, unreal world		Denial.
Denial		Personal decision: he has to be positive.
Power		Positive attitude as a coping mechanism.
Coping strategy		Initial timeline: shock → denial/dream world → personal decision: adopting a positive attitude.
Positive attitude		What was it that made him change his coping style then? He needed to protect himself in a way?

Following these steps, emergent themes from the participant were grouped into subordinate themes. For George's account the subordinate themes are presented in the table below (numbers indicate lines in the transcript):

Table 4.2. Organisation table of subordinate themes from emergent themes

Subordinate themes	Emergent Themes
<i>Leukaemia in disguise</i>	<ol style="list-style-type: none"> 1. Leukaemia hard to make sense: 22, 27-30, 80-2, 86-7, 103, 1451-3, 1457-8, 2059-62, 2085-7 2. Leukaemia a surprise: 24 3. Leukaemia in disguise as infection: 25-27, 585-88 4. Searching for clues of leukaemia: 231-2, 234, 369-71 5. Leukaemia illogical: 587-8 6. Initial causal attributions: 34-6, 42-3, 2092-8 7. Leukaemia as punishment: 35-36 8. Leukaemia incurable: 380-2 9. Body as failure, "body blow": 244-5, 372-4, 382-3, 1433-36, 2163-5 10. Efforts to understand illness: 1452-3, 1457-8, 1465-7, 1500-1
<i>World of emotions</i>	<ol style="list-style-type: none"> 1. Leukaemia a shock: 45, 244-5 2. Sense of unreal world: 47-9 3. Being depressive: 132-3, 246, 656, 660-1, 666, 861, 863-4, 925-7, 1563-4 4. Fear of recurrence: 234 5. Emotional distress from relapse: 250, 379 6. Apathy, passive behaviour: 266-7, 271-2, 281-2, 295, 7. Emotional impact of hospitalisation: 580-1, 589-90, 593-5 8. Aggressive behaviour: 873-5, 879-884, 892-4, 925-7 9. Fear of death/not accepting death: 1156-1161, 1168-73, 1201-5 11. Survivor's guilt: 1186-1189 12. Loneliness in hospitalisation: 846-7 13. Guilt: 157-9
<i>Embodiment of leukaemia</i>	<ol style="list-style-type: none"> 1. Patient as expert: 107, 111-112, 225, 230, 236-7, 379-82, 403-5, 409-410, 1129-1134, 1324-8, 1433, 1437-8, 1507, 1511-17, 2173-9 2. Fatigue as side effect: 149, 907, 1394-6 3. Preconceptions re chemotherapy: 145, 155-9, 169-70, 183-5, 190, 198-9 4. Experience of treatment: 200, 207-9
<i>The social world</i>	<ol style="list-style-type: none"> 1. Worries of trivial matters: 325-6 2. Peer support: 470-1, 1121-3, 1129-34, 1955-2014, 2040-2 3. Support from nurses: 471-4, 1138-9, 1145-7 4. A shrinking world: 522-3, 631-7 5. Protective of the mother: 701-4, 797-803 6. Illness and social world: 723-4, 730-4, 746-7, 756-7, 1974-8, 1982-4 7. Support from friends: 748-9, 772-3 8. Sense of connectedness with strangers: 1183-6
<i>A holiday in prison</i>	<ol style="list-style-type: none"> 1. Patient surrendering to the experts: 69-70, 591 2. Hospital a new society: 151-4, 467-473 3. The Prisoner: 35-36, 467-8, 512-3, 568-71, 580-1, 588-91, 593-5, 634-7, 1035, 1051-2, 1066-70, 1089-92, 1184-5, 1439

Subordinate themes	Emergent Themes
	<ol style="list-style-type: none"> 4. "A holiday in prison": 534, 556-9, 563, 568-571, 580-1, 1066-70, 1074-6, 1089-92, 1402-6, 1957-67 5. Experiencing death of others: 1141-44, 1156-7, 1158-9, 1193-7 6. Hospital, taking away senses: 1391 7. Doctor as authority: 922-3, 942-3, 2068-9 8. Home as a sanctuary: 1036-7, 1051, 1374-5, 1392-3
<i>Coping with leukaemia</i>	<ol style="list-style-type: none"> 1. Initial reactions to diagnosis: 696-8 2. Failed coping: 855 3. Cognitive coping, positive attitude: 50-52, 68-69, 133-5 4. Denial: 48-9 5. Avoidance as a protective mechanism: 68, 137-9, 703, 709, 714-5, 1170-3, 1201-2, 1630-1, 1638-9, 1675-79 6. Efforts to be positive, optimistic, hopeful: 71-3, 131-2, 395, 1568-70, 1575-81, 1585, 1589-93, 2123-4, 2250-1 7. Personal experience a reference to understand leukaemia: 96-8, 231-2 8. Separating from father's experience: 103-5 9. Autosuggestion: 136-7, 139-140, 671-2, 1558-9 10. Stoicity: 140, 508, 1173-4, 1209-10, 2061-2, 2072-3, 2097-8 11. Coping strategy, cognitive processing: 251-3, 671-5, 1563-70 12. Fighting spirit (coping style): 253-4 13. Practical problem-solving: 255-6 14. Rationalising: 486, 379-82, 1486-7, 2066-7 15. Efforts to cope, practical coping : 524-6 16. Belief system on positive attitude: 668-671 17. Positivity as part of the treatment: 677-8 18. Belief system, mind-body: 682-3, 1554-59, 1715-19, 1733-37 19. Drug abuse: 864, 868-870 20. Bucking up (coping style): 1295, 1307 21. Difficulty accepting the consequences of treatment: 915-6 22. General knowledge as frame of reference: 29-30, 40-1, 80-2, 91-2, 667, 1550-2 23. Understanding experimental treatment: 111-3 24. Initial thoughts, resignation (passive): 125-7, 129-30, 383 25. Cancer perceptions: 126-7
<i>Counting losses</i>	<ol style="list-style-type: none"> 1. Worries of distant future: 307-12 2. Loss of distant future: 320-1 3. Independence as a life choice: 808-812, 821, 1396-7 4. Efforts for normality: 1036-1041
<i>The self</i>	<ol style="list-style-type: none"> 1. Self-blame: 42, 126-7, 130, 1463-4, 1495-1500 2. Difficulty in dealing with the new reality: 46, 1563-4 3. Self-identity preservation: 291-2 4. A changed, better person: 296, 2102-5 5. Being a loner (personality characteristic): 462-3, 468-9, 765-6, 815-7, 831, 1972-73 6. Low self-esteem: 764-5, 770-4
<i>Assimilating leukaemia</i>	<ol style="list-style-type: none"> 1. Purpose in life: 253, 1593, 1597-1605, 2124-5, 2140-2150 2. Reprioritising values: 330, 358 3. Given a second chance: 341-2, 356, 384-5 4. Impulsive behaviour: 343-347, 1884-99, 2112-4 5. "Living for today": 330-1, 337, 348-9, 453-7, 2105-8, 2118-9 6. Life in small things: 1376, 1385-87 7. Realising mortality: 1646-50

A detailed presentation of the superordinate themes for each participant group is provided in Chapters 5 and 6.

As the researcher familiarises themselves with the analytical process, the analysis can move to deeper levels of interpretation, however, Smith et al. [352] admit that, in the case of large sample sizes (more than six participants), ‘almost inevitably the analysis of each case cannot be so detailed’ (p. 106). A proposed way to manage larger datasets is to focus on each individual case, and only when all cases have been analysed to look through points of similarity [352]. The researcher followed this advice, with the analysis process commencing only when the data collection had been completed.

The next steps of the analysis process included inductive thinking from the part of the researcher. The aim was to create an account of the findings that would be relevant and sensible to the professional background of the researcher. In doing so, the researcher examined different types of metaphors that could represent the findings of the study. At this stage, combining the themes (emergent themes at first, and subordinate themes later) in different ways aided the final development and organisation of the superordinate themes. These variations were followed by performing checks of the transcripts to ensure that each theme was represented by a sufficient amount of examples within the transcripts. This process enhanced the rigour of the analysis and facilitated identification of exemplar quotes that were included in the final written account.

4.7.2 Quality

Following Yardley’s [386, 387] four principles as they were detailed in Section 3.5.5, a presentation of how these four principles were addressed in this IPA qualitative study follows.

Sensitivity to context

In this study a number of different techniques were adopted in order to establish sensitivity to context. The selection of this specific group of participants, patients with acute leukaemia and their carers, posed several difficulties in terms of accessibility. The researcher, acknowledging the fact that these people were not an easy population to target, worked closely with the clinical teams in both sites from the early stages to enhance the recruitment of participants to

the study. Building this rapport with the gatekeepers was the reason for the successful and timely recruitment as well as the low attrition of participants.

Sensitivity can be also present itself during the process of data collection, when conducting the actual interviews [352]. In order to improve the interview technique, apart from the initial interview when piloting the methods, the researcher attended specific workshops on in-depth interviewing and tested the interview topic guide in a 'mock' interview with a colleague. The researcher was always aware of the interview process, by showing empathy to what the participants disclosed, always putting them at ease. For instance, in one case a participant became quite emotional when describing how he was treated at the hospital regarding his treatment options. The researcher, after stopping the voice recorder, had a discussion with the participant for half an hour before the interview could continue after obtaining the patient's consent.

This sensitivity to context continued in the analysis process. In order to make sense of how participants made sense of their experience of acute leukaemia, close attention to each individual account and on the particularities of each participant was required. This objective was achieved by providing a brief presentation of each of the study's participants at the beginning of each of the findings chapters (see Sections 5.2 and 6.2 for a presentation of patients and carers respectively).

Commitment and rigour

Commitment refers to the degree of attentiveness to the participant during data collection and the care with which analysis is carried out during the analysis process. Smith argues that for this type of research this commitment is synonymous with sensitivity to context [352].

Rigour in this project is demonstrated from selecting a suitable sample to answer the research questions; considering the difficulties in recruitment, the researcher aimed for the sample to be as homogeneous as possible. Conducting a good interview also demonstrates the level of commitment and the how rigorous the project is [352]. The researcher showed empathy and tried to keep a balance between how close and how distant she should be from the participants. She tried to be consistent in using probes when identifying important clues in the participants' accounts. Lastly, the completeness of the analysis undertaken is another element of rigour. In IPA, the analysis is interpretative, moving beyond the mere description of what is being said to what it means for the participant. Each of the superordinate themes is supported

with quotes from all participants' accounts. Also, for a subordinate theme to be included in the final account, it should be present in more than half of the accounts.

Transparency and coherence

Transparency of the research process is demonstrated in this project through describing how the steps were followed in each step of the project. Moreover, demonstrating how the superordinate themes were developed from the input of each individual case (details can be found in subsequent Chapters 5 and 6) was achieved through the use of tables. An example of a fully worked transcript is also provided in Appendix 5.

Coherence is demonstrated from how well the arguments are linked together with the findings and whether they flow logically from one process to the next. Another way to show coherency is the level to which a study fits the theoretical underpinnings of the selected approach. In adopting an IPA approach, specific care was taken during the analysis and write-up of the findings to demonstrate both phenomenological and hermeneutic statements.

Impact and Importance

The findings of this PhD study aspire to offer a unique lens through which to view the processes people use in order to make sense of acute leukaemia. It is hoped that the findings of this study will form the basis of the development of future interventions for people affected by this illness and their families. For a more detailed discussion of the findings, see Chapter 7.

4.8 Reflexivity

Reflexivity has already been defined in Section 3.4.2 and refers to the researcher's efforts to develop self-awareness [370]. Reflexivity is linked to the quality and credibility of the project, as the researcher is called to acknowledge the different, in many cases covert, ways he/she can influence the study [402-406]. Indeed, reflexivity applies to 'both the process and the product of the research endeavour' (p. 8) [407]. A reflexive account, however, does not mean

that biases are limited, but it is a way to make apparent the existing issues that will then facilitate a more accurate interpretation of participants' accounts [402].

Reflexivity regarding the data collection process has been suggested to involve empathy [407, 408], reciprocity (i.e. sharing experiences and emotions with participants) [409, 410] and juggling multiple roles (researcher versus clinician) [406, 407, 410]. During the course of the interviews in the current study, the researcher used her empathic skills as a means to enhance rapport in relationships with participants. The researcher was introduced to participants as a qualified nurse conducting a study as part of her PhD. As a consequence, in certain occasions participants wanted to draw on her professional expertise regarding the discussions raised during the interviews. It was then the researcher who emphasised her current role (at that point) as a researcher. However, whenever participants highlighted issues that, to her professional judgement, required follow-up by the clinical team, she flagged the issues to the local collaborators and issues were resolved by the clinical team, on the basis of the aforementioned ethical guidelines. After the end of each interview the researcher completed a reflexive sheet detailing her thoughts about the interview that had just finished (see Appendix 4). This was done in an attempt to note down any prejudices regarding the discussions raised during the interviews. Separating the researcher's role and nurse's role was necessary because the researcher had previously worked as a nurse specialist in a Haematology/Oncology unit at a University Hospital in Greece. However, because her time was devoted only to conducting the current study and she did not work as a nurse in the study sites, it was easier to maintain the role of the researcher. Instead of sharing her interview experiences with participants, the researcher turned to her supervisors for support and to share her thoughts and emotions after the interviews in the form of a debriefing session, a strategy which is also suggested in the literature [402]. Moreover, a reflexive account was kept throughout the study to consider the impact and interaction between the researcher and the research process.

Reflexivity during the data analysis process involved the maintenance of a personal reflexive diary, which started off with a 'statement of positionality' [402], that is to say the pre-assumptions and knowledge of the researcher, and continued with the range of different emotions and considerations at the time of analysis. Once again, her previous professional expertise and experience was noted down and revisited throughout the analysis process to ensure transparency and rigour. In engaging with the participants' accounts, the researcher put particular emphasis when she interrogated the text, always keeping a balance between the theory of empathy and the theory of suspicion. This proved to be also helpful when the researcher moved from the patients' to the caregivers' dataset to clarify the different processes between the two groups.

4.9 Chapter summary

This Chapter discussed in detail the different issues pertaining to the selected research methods for this PhD study. Also, ethical considerations regarding the research process were addressed, followed by a presentation of the data analysis process. Finally, the issue of reflexivity was presented in relation to this project's quality and credibility. The following two chapters will present the findings of this study.

CHAPTER 5 – Findings: Patients’ making-sense processes

5.1 Introduction

This chapter provides the first part of this PhD study’s findings; those from the patients’ perspective. Initially, participants’ characteristics are presented in brief with a demographic and contextual description, followed by an overall description of the superordinate themes. Subsequently, each superordinate theme is detailed with a specific focus to answer the first research question of the study: how do patients make sense of their diagnosis of acute leukaemia? Each subordinate theme is supported by participants’ quotes. The large dataset obtained offered a variety of choices to the researcher in order to supplement her arguments. Despite the guidelines for IPA suggesting each theme should be supported with quotes from every participant, the decision was made to support each superordinate theme with quotes from the entire group by presenting quotes from two participants for each subordinate theme. The richness of the acquired data gave the researcher a range of different quotes for each subordinate theme to choose from; however, due to the spatial restrictions of this thesis, the quotes were selected on the basis of how illustrative they were of the relevant sub-themes. These were also discussed with the researcher’s academic supervisors. The extensive, at times, length of participants’ quotes is acknowledged, however, this strategy offers more context to the reader and makes subsequent arguments and analysis elements more straightforward.

Analysis revealed that patients make sense of acute leukaemia through three processes: decay, transformation and growth. The presentation of these processes follows a logical rather than a temporal order, as the chronological mapping of the processes lay beyond the purposes of this study.

5.2 Participants

Over a period of twelve months, local clinical collaborators approached a total of thirteen consecutive patients diagnosed with acute leukaemia who fulfilled the inclusion criteria of the study. Two patients declined participation in the study: one was not interested, and one due to

being overly stressed. Also, one patient died just after the first induction treatment. Ten patients agreed to participate in the study, all of whom were interviewed twice. Contextual information is provided for each of the participants in the following section, while their demographic characteristics can be found in *Table 4.1* below.

Table 4.1. Patient demographic characteristics

Participant	Age	Educational background	Employment status	Marital status	Type of acute leukaemia	Weeks from diagnosis
Emma	67	High School	Retired	Divorced	AML (relapse)	7
Ian	31	University	Employed	Single	ALL	11
Andy	59	College	Retired	Married	APML	8
Stephen	20	College	Not employed	Single	APML	8
Robert	66	University	Employed	Married	AML	5
Molly	29	College	Employed	Partnered	APML	6
George	46	College	Employed	Single	AML (relapse)	4
Kevin	23	High School	Employed	Married	ALL	4
Mary	21	University	Not employed	Married	ALL (relapse)	4
Bruce	72	High School	Retired	Married	AML	5

Emma

Emma was initially diagnosed with AML in 2006. Five years later, in 2011, her acute leukaemia relapsed. Divorced for many years, she lived with two of her three grandchildren and was responsible for their upbringing since she gained their custody. Both interviews took place in a quiet room in the hospital.

Ian

Ian was diagnosed with ALL at the age of 31. He also had mild apraxia, a disorder of motor planning that affected his speech; his cognitive function remained intact. He was working on a full-time basis when he received his diagnosis. He lived alone; his parents had been divorced since he was young and his mother came every two weeks to spend time with him during the induction treatment. Three months after his diagnosis, he was transferred to the South of England to a specialised centre to continue his treatment. The first interview was conducted in the hospital, in his isolation room, and the second one in a quiet meeting room at the University of Dundee.

Andy

At the age of 59, Andy was diagnosed with APML; this being the second time he had received a diagnosis of a serious illness. He was diagnosed with multiple sclerosis (MS) in 2000. He was the only participant to have a cause for his leukaemia: a specific medication he received for the treatment of MS symptomatology that is known to cause leukaemia as a long-term side effect. He lived with his wife. He attended weekly oxygen therapy sessions in a decompression chamber where he would meet with peers who had also been diagnosed with MS. Both interviews were conducted in the hospital in a quiet room.

Stephen

Stephen was diagnosed with APML at 20, just after coming back from holidays. He was about to start his University degree but the illness changed his plans. Being diagnosed with acute leukaemia did not stop him from exercising. When he was diagnosed he had to make a decision on the type of treatment he would follow: conventional, or a more experimental one. Both interviews were held in the hospital during his treatment.

Robert

Robert was diagnosed with AML at 66. He was still working full-time at the time. His diagnosis came without warning, from a routine blood test to determine the suitability of his changed prescription for his diabetes medication. During the first treatment he picked up a fungal infection that prolonged his hospital stay for two weeks. At the time of the first interview his pulmonary function was just starting to recover. Both interviews were conducted in his isolation hospital room.

Molly

Molly was 29 when diagnosed with APML. She lived with her partner and worked full-time for a business involving social interactions. After diagnosis she had to reduce her work to part-time hours. Her partner had previous cancer experience (his mother died of cancer) and, according to Molly, that was the reason he did not cope very well with her acute leukaemia. Both interviews were held in the hospital during her treatment appointments.

George

George was diagnosed with AML for a second time at the age of 46. His father had died of AML several years ago. He used to work off-shore. He lived alone in his flat and chose to have a distant relationship from his brother and sister. After the end of his participation in the project he was scheduled for a BMT, as his sister was a compatible donor. Both interviews were conducted in the hospital.

Kevin

Kevin was 23 when he was diagnosed with ALL. He self-admitted to the hospital after some delays with his GP practice. He was engaged and just had moved in with his fiancée to their new home. ALL postponed their wedding plans for the following year. Both interviews were held in the hospital.

Mary

Mary had been initially diagnosed with ALL at the age of 15. Just after reaching her five-year survival of being disease-free, her ALL relapsed and she was admitted to the adults' hospital. She had been married for three months and she was in her final year of art school at university. Her young husband, Roy, worked off-shore, but after her diagnosis of relapse, they both moved into her parents' home. After the end of her participation in the study, Mary was about to make a decision of whether to have a BMT or go on with another chemotherapy cycle. Both interviews were conducted in the hospital.

Bruce

Bruce was diagnosed with AML at the age of 77. He lived with his wife and their two dogs. They had lost their only son several years ago from a mental illness. At the time of the first interview he was left with the idea that he had one more week to live, due to a communication fall-out with his healthcare team. Later, the researcher informed the nurse specialist, who was also the local collaborator of the study, and the communication issue was successfully addressed. Both interviews were conducted in the hospital.

5.3 The tree of equilibrium: decay, transformation and growth

In this study, patients made sense of their diagnosis of acute leukaemia by engaging in three processes: decay, transformation and growth. These three superordinate themes/processes are further organised in nine subordinate themes, which were developed from the emergent themes of each individual account. *Table 4.2* below provides an overall organisation of the findings. For a subordinate theme to be included in the organisation of the superordinate themes, it should be present in at least 50% of participants' accounts. The presence of the nine subordinate themes in each of the participants can be seen in *Table 4.3*.

Table 4.2. Master table of patients' findings

Superordinate themes	Subordinate themes	Emergent themes
DECAY	<i>Leukaemia in disguise</i>	Leukaemia in disguise/invisible Leukaemia as body blow Leukaemia a fast track illness Leukaemia fatal Leukaemia putting life on "hold" Leukaemia taking away choices Leukaemia restrictive
	<i>A holiday in prison</i>	Imprisonment Experiencing hospitalisation Patient-doctor relationship dynamics Information flow
	<i>Coping with leukaemia</i>	Avoidance — distancing — denial
	<i>Embodiment of leukaemia</i>	Experiencing treatment/side-effects Experiencing fatigue
	<i>The social world</i>	Family worries/family protecting Social impact of leukaemia/impact on interpersonal relationships
	<i>The self</i>	The impaired self Self-blame
	<i>Counting losses</i>	Loss of future Loss of normality Loss of control Loss of independence
	<i>World of emotions</i>	Living in uncertainty Fear Shock of diagnosis Sense of unreal world, emotional Numbness Loneliness Depression
TRANSFORMATION	<i>Leukaemia in disguise</i>	Leukaemia, an individual illness Mental images of leukaemia Leukaemia, hard to make sense Terminology of an illness
	<i>A holiday in prison</i>	Imprisonment Experiencing hospitalisation

Superordinate themes	Subordinate themes	Emergent themes
		Patient-doctor relationship dynamics Information flow
	<i>Coping with leukaemia</i>	Using old frames of reference Comparing – contrasting Building knowledge-understanding Cognitive processing
	<i>Embodiment of leukaemia</i>	Altered body image Experiencing treatment/side-effects
	<i>The social world</i>	Affected roles Family worries/family protecting Social impact of leukaemia/impact on interpersonal relationships
	<i>The self</i>	Altered self/old self v. new self Self-preservation
	<i>Counting losses</i>	Striving for normality/daily routine Efforts to regain control
	<i>Assimilating leukaemia</i>	Realising own mortality Re-prioritising values
GROWTH	<i>A holiday in prison</i>	Patient-doctor relationship dynamics
	<i>Coping with leukaemia</i>	Being positive and hopeful Stoic acceptance
	<i>Embodiment of leukaemia</i>	Patient as expert
	<i>The social world</i>	Sources of support
	<i>The self</i>	A changed better version of self Pride
	<i>Counting losses</i>	Maintaining control Maintaining normality
	<i>Assimilating leukaemia</i>	Leukaemia putting life into perspective Given a second chance

Table 4.3. Presence of subordinate theme in each participant

	Emma	Ian	Andy	Stephen	Robert	Molly	George	Kevin	Mary	Bruce
Leukaemia in disguise	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
World of emotions	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Embodiment of leukaemia	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
The social world	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
A holiday in prison	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Coping with leukaemia	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
Counting losses	YES	YES	YES	YES	YES	YES	YES	YES	YES	YES
The self	YES	YES	YES	YES	NO	YES	YES	YES	YES	YES
Assimilating leukaemia	YES	NO	YES	YES	NO	NO	YES	YES	YES	YES

Acute leukaemia creates a state of imbalance for the individual, which initiates processes in order to restore the previous balance, to find a new state of equilibrium. These three

processes seem to occur concurrently and manifest in various ways. Hence, each of these three superordinate themes involves a number of subordinate themes. Equally, these themes may be present in more than one process but involve different qualities. For instance, in the subordinate theme, 'a holiday in prison', there are elements of all the three major processes; an example can be seen in George's extract below:

*... so sometimes when I'm thrown into, you know like a, a six-bed ward, eh a four-bed ward, I find it a bit ... you know it takes me a wee while to ... to, to get to know people, but because we're all in the same boat we usually all get you know quite friendly with each other, em and the nurses are fantastic here, a lot of the nurses were here when I was in last year as well which made a huge difference to have the ... "Oh, hello ..." and you, you know what I mean? **George***

In this extract George starts from a state of decay: he is "thrown into" a hospital room, like a prisoner, a man with no power of his own. He, then, progresses to transformation: "it takes a while to get to know people", he needs time to adapt, the transformation takes time to take over from decay, to go from feeling like a prisoner to having "friends", to start feeling comfortable in the new environment. Eventually, there is a glimpse of growth: the same "fantastic nurses" were again there when he experienced relapse, which gave him more confidence.

Maintaining equilibrium among decay, transformation and growth resembles the life of a tree (see Figure 4). Indeed, at a given moment leaves may wither, while others are just starting to grow, and, at the same time, others are in full bloom. This metaphor was selected as it captured the complexity of how meaning-making processes occur. The three processes that take place in order to preserve the equilibrium are detailed in full in the subsequent three sections.

Growth

Transformation

Decay

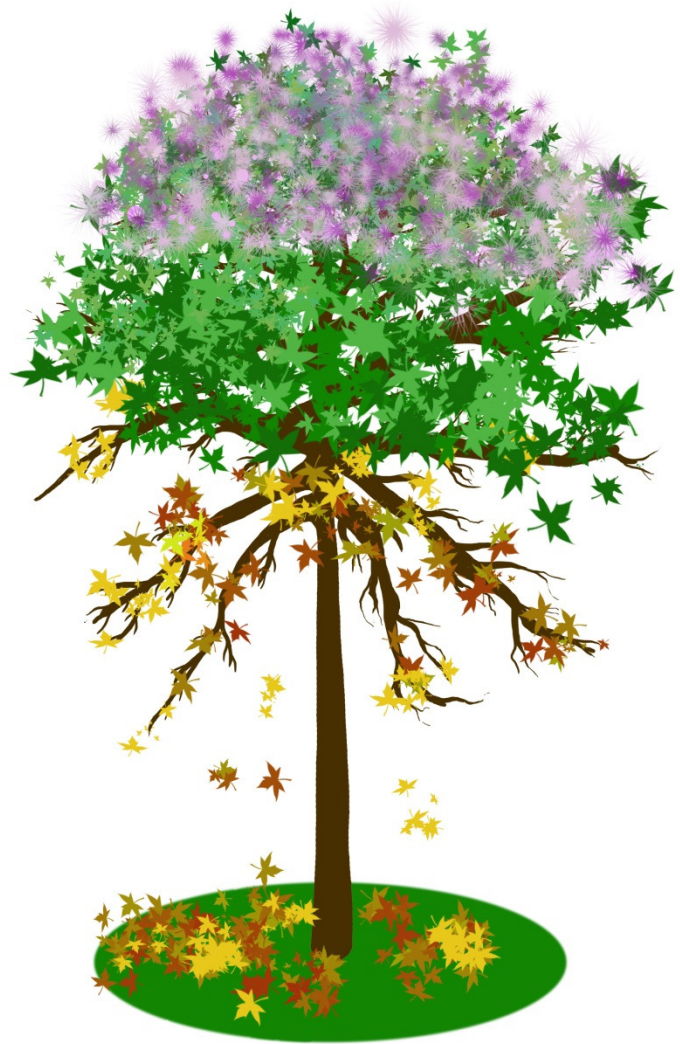


Figure 4. The tree of equilibrium: decay, transformation, growth.

5.4 Decay

As patients attempt to make sense of acute leukaemia they undergo a process of decay. Decay appeared to be a more potent process when compared with transformation and growth, perhaps due to the point at which the interviews took place in the cancer journey. Participants were interviewed only weeks after their diagnosis (either of the first occurrence or relapse) which was followed by immediate hospitalisation and treatment initiation. For these participants decay was demonstrated in a number of subthemes, namely leukaemia in disguise; a holiday in prison; coping with leukaemia; embodiment of leukaemia; the social world; the self; counting losses; and world of emotions. This section analytically presents each of these subthemes.

5.4.1 Leukaemia in disguise

One of the most prominent signs of decay was acute leukaemia's disguise as infection. The illness remained invisible for the majority (n=9) of participants. Consequently, the diagnosis was conceived as a body blow. This sense of blow escalates as everything is put on fast-track mode: hospitalisation, intensive chemotherapy, supportive treatment. At the same time, the rest of the person's life is put on hold; this forced paucity of the normal life-course, a sense of being static, is another aspect of decay.

For example, in the following quote Ian, an active 32-year-old man describes how he got his diagnosis of ALL:

I mean it was quite a shock, it was quite a shock obviously, I thought I had a virus or something or other, I wasn't expecting anything serious, and also it, I hadn't felt particularly ... I hadn't ... I hadn't felt and, at the start of my treatment didn't feel particularly, all that ill either, so the odd situation of being ... I mean I remember when they wanted to give me a transfusion, when I came in kind of, arguing as to whether that was necessary or, or not 'cause I felt perfectly, I felt, feeling OK. So the odd situation of a blood test telling me I'm quite, telling ... being told I'm quite ill based on a blood test, but without actually feeling, you know ... I, I've felt much worse with much more minor things, like hangovers to be honest. Ian

In the above extract, leukaemia was camouflaged behind a viral infection. It is noticeable how Ian struggles to finish his sentences, a sign of an internal tension or an indication of underlying

cognitive processing to make sense of something that, in his mind, makes no sense. A single blood test, something considered to be a routine practice, carried the news of a serious and potentially life-threatening illness: acute leukaemia. This was an “odd” situation for him, particularly, as he says that he did not feel ill. Ian’s difficulty to understand what was happening is even more striking when he questioned healthcare professionals’ efforts (i.e. a blood transfusion) to provide the supportive care required. It is quite a common assumption that serious illnesses manifest with serious signs and symptoms. Acute leukaemia fails to be placed under this category, with symptoms resembling flu, and obviously this makes it harder for patients to understand it. The process of decay here is indicative of how an invisible to the person serious illness can interfere in patients’ process of making sense.

Participants in the study described extensively their journeys to diagnosis because of leukaemia’s particular invisibility traits. One such long journey to diagnosis due to leukaemia’s disguise is Stephen’s below:

*I had been to the doctor’s so many times like in that spell, em, but like I kept getting told it was a virus and then I got some antibiotics and then it did actually settle down for a wee bit, like I was feeling OK, em and then I went away for a weekend in Manchester for my mate’s birthday, like I had been drinking and that again so, and then I felt awful, I came back and started going to the doctor’s again, and again at first I was getting told that I had a virus but a, a massive bruise appeared just on my side, so then eventually one of them took a blood test and then, like I had been told they thought it was glandular fever that I’d had [m-mmm] so then I got this blood test taken and a couple of hours later I got told that I had to go to, here, for further results or something, or tests and then I think that, that night I got told that he thought I had leukaemia which, going from thinking that I had glandular fever or a virus to find out you had cancer was a bit of a shock ... to the system. **Stephen***

Stephen was 21 years old when he received his diagnosis of APL. His journey involved trips to GP practices starting off as a viral infection, moving to glandular fever to finally receiving the diagnosis of leukaemia. The first visible sign of leukaemia was his bruising. Reasonably, the absence of visible signs of leukaemia at first and the fact that he was only 21 years old could never lead him to think that he could actually have leukaemia. This is further explained in the ‘world of emotions’ subordinate theme (section 5.4.8); inasmuch as leukaemia has the trait of being invisible, he was still bewildered by the news of his diagnosis.

Patients’ making-sense processes at the very beginning of their cancer journey can entail a number of obstacles to overcome. Surely, the absence of visibly recognisable symptoms – one

of the specific characteristics of leukaemia – may be a reason why, at least during the initial phase, patients struggle to understand how and why leukaemia has happened.

5.4.2 A holiday in prison

After receiving the diagnosis of acute leukaemia, the treatment initiation is imperative. Living with the diagnosis and treatment-related side-effects aside, patients have to deal with prolonged hospitalisation. The process of decay in this subordinate theme became more evident when participants experienced hospitalisation as a state of imprisonment. This sense of imprisonment depended on the dynamics within the patient-doctor relationship.

George was 46 years old when his AML relapsed. During the interviews he referred to his hospital stay as “a holiday in prison”:

George: *I'm not the most em gregarious of people, you know I, I'm quite a loner [OK] so sometimes when I'm thrown into, you know like a, a six-bed ward, eh a four-bed ward, I find it a bit ... you know it takes me a wee while to ... to, to get to know people. [...] it's almost like a holiday really [both laugh] a holiday in prison! [...] it's just 'cause you know they're all institutionalised rooms, you know with the grey paint and I used to work off-shore in the early 70's and we always used to say that was like a prison but you're getting paid for it you know 'cause you're in a tight confined space and, and I, I say jokingly... [yeah, yeah] ... you know em, but that's, that's what I feel here, you know you're in little cells and eh, because ... because my eh counts are so low, I'm not really allowed to leave the ward so eh, you know it's like ... it's almost at the bars ... “can I get out for a walk?” [...] That's another problem I find in here, is you lose days, it's like what day is, is this Tuesday, no it's, it's Thursday or is it Saturday? And you ... it, it's very easy to sort of lose track oh time. [...] 'Cause some, sometimes you know because of the treatment it can be a solid three weeks you're in a room, or you know you're on the treatment and you can't go anywhere, and you know even, like I say an afternoon can make so much of a difference, well certainly to me ...*

Constantina: *So do you feel like you're, you have been institutionalised being in the ward?*

George: *At the moment – no, but last year, yeah, yeah, but as it went, you know in the later stages yeah. You know 'cause eh, you get woken at 6 for your bloods, you get your breakfast at 8, your bed's changed by 9, the doctors are round between 10 and 11, your dinner's at 12 ... you know what I mean it, it is all sort of regimented ...*

That George felt like a prisoner became evident from the very beginning of the interviews. He was “thrown” in a six-bedded ward, like a person with no will or power of his own. He resembles a prisoner thrown into a cell together with a number of strangers, the cellmates – patients. During his first interview he came up with the phrase “a holiday in prison” to describe his institutionalisation. Although he chose to compare his stay to a “holiday”, this description serves only as a euphemism to the hard reality of how he feels: a prisoner “*at the bars*”. Indeed, in his comparison between staying in hospital and the time he worked offshore, all the basic elements of imprisonment are present: the confinement, the grey colour of the building, the oddness of remaining willingly inside, the everyday routine, and the loss of keeping track of time. His decay process is even more evident in the following extract:

*I found that the first time I was in here, some days if I'd picked up a little infection that could may be 2, 3, 4 weeks before I'd be allowed to get a pass to get out, and I'd feel perfectly healthy, and it's like, "Sorry, we can't let you out," and you're just sitting there going [sighs] you know, getting really sort of frustrated. Em, but, I, I, I go with the doctors' orders, you know they're they experts, if they're saying it's not right for me to go out, that's fair enough, but at the same time, you know sometimes I was almost pulling my hair out if I had any, because I was... "Just get me out of here!" [laughs] even for an afternoon, you know ... **George***

George was “*pulling his hair out*” because he had to spend more time in the hospital. His agony is conspicuous: due to his chemotherapy treatment he suffered from hair loss, yet in sight of having to stay longer in his room, he could even pull his remaining hair out. Literally, from a spatial perspective, patients feel like prisoners by being obliged to stay in a hospital room in order to prevent infections. In reality, they are prisoners of their own body: due to the low blood counts they have to stay in their room to help prevent infections that could cause delays in treatment and could potentially be fatal. Albeit, their state of mind is still functioning normally, this loss of freedom can cause a sense of agony, suggesting another sign of decay.

To further support this decaying element in hospitalisation, Ian below described the specific characteristics of this institutionalisation:

And hard to know what'll be a good outcome as well, I mean as far as people, you know the effects of institutionalising people in prisons or in the army obviously aren't great in terms of how it changes in the long term. I mean you become institutionalised to a fair extent I mean, becoming used to having to wait for someone to bring me food and water ... or ... [long pause] ... being dependent on other people to sort out things which I would normally do myself without thinking about it. And also I'd be quite entitled to walk out of here but it, it's apparently not the best idea so ... [long pause] ... being kept confined in an institution partly based on my

willingness or compliance with doing so that, you know it obviously wouldn't be the case if you well, [...] in some open prisons it is the case that people go out on Day Release and can't, don't bring themselves back again but [long pause] on place, being here but there's quite heavy restrictions on what I can do and, it's, it's a kind of ... enforce is the wrong word, but it's a kind of institutionalisation where the alternative to the institutionalisation aren't particularly positive from my point of view. Ian

Although this perception is included in the subtheme 'counting losses' (section 5.4.7), it is noticeable in this extract how Ian feels institutionalised. The hospital for him is a different world that strips patients off the control over their own lives. The hospital is an institution, almost hostile, compared to army and prison, but differs in the sense that patients have no alternative but to choose to stay within. Ian guides his efforts to rationalise his confinement, but eventually he is not happy with the fact that he has no other choice.

For patients with acute leukaemia, this confinement is odd; one that they have to accept because of their life-threatening condition. The hospital can be hostile during the initial period when everything is new and unknown, and it is at that time when the process of decay is more prominent.

5.4.3 Coping with leukaemia

A number of different coping styles were identified during the analysis that participants employed in order to make sense of acute leukaemia. Within the process of decay, three negative coping strategies were: denial, avoidance and distancing. Participants did not necessarily use these three strategies in isolation; rather they interchanged them with others identified within the processes of transformation and growth.

Kevin was a young adult of 23 years being diagnosed with ALL just after he started living with his fiancée. This is how he dealt with leukaemia initially:

So I don't look up any, I haven't been on the Internet, I haven't looked at any books. I did look at the book, they gave me a leaflet home [m-mmm], and [...] and the first page said "ALL can be rapidly fatal", so I closed the book and I haven't opened it since [laughs], and I haven't read it, so. I just, that's not helping me at all, em I don't, I don't have, like I say I don't have any desire to, to find out any statistics, [...] to be honest with you again though it's, I don't want to know really what happens, because I don't want to know what can go wrong, you know what I mean? [mmm] So I haven't really, the doctors tell you what

they're looking for and the characteristics of the cells and what they're expecting to do but I don't really ... [understand] or want to really understand, because then I'll start thinking about what happens when they start going wrong and then, and like I say as far as I'm concerned nothing's going to go wrong, so I, I, I'll keep it at, they, they just need to tell me the, if it's working or if it's not working and I'm, I'm happy wi that. Kevin

Here, Kevin's coping mechanism is avoidance. At the very early stages of his hospitalisation he chose to protect himself by shutting down all unnecessary noise: he was given an information flyer related to his illness that he decided not to read the moment he came across the word 'death'. He was in the process of coming to terms with his diagnosis of ALL and thinking about the possibility of leukaemia being fatal scared him. Knowing of this possibility, he went on to make a cognitive decision to shut this process down. Instead, he selected to take in only the information that applied to his individual circumstances. Later on during the interview, he admitted that at that stage he actually did not want to really understand what leukaemia was and how it worked inside his body. He only focussed on the information he received from the clinicians regarding the progress of his treatment. Choosing not to understand, putting the entire leukaemia into a type of 'sleep mode' is not uncommon for a person facing a life-threatening condition. Arguably, utilising more passive coping strategies may seem effective at the start but they do not have a long-lasting effect. This avoidance can subsequently have a negative impact in a person's making-sense process.

However, patients whose coping was in decay might not have been due to leukaemia itself. George provides an example of how he could not cope in general before the second time when his leukaemia relapsed:

With difficult situations? E-m ... I didn't cope very well actually. E-m [sighs] well I used to get really depressive, it's only this year I've actually taken these pills, em I used to get quite depressed about things and I'd get very moody and not speak to people and ... em, I self-medicate wi cannabis [...]em ... and that's about it really, you know eh ... for years, as well as recreational use, I, I was using cannabis to ... where I should have been getting anti-depressants basically you know [...] A sort of ... [sighs] ... more stressed than angry but yeah there was an anger in it, you know I'd, I'd get frustrated about things and eh, you know at work if ... you know a colleague had done something really stupid or done something totally against what I'd asked them to do or something, you know I'd get ... I, I wouldn't get physical [...] I'd get really wound up and I'd end up sort of kicking walls and, you know punching walls and stuff outa frustration and sort of anger. George

George describes how his depressive persona did not help him cope with difficult situations in general. He self-medicated with cannabis in order to cope. It was during the period of

remission that he decided to seek medical advice. His coping was in complete decay, and this occasionally affected his social interactions. George here is not proud of his choice; he hesitated on a number of instances, implying discomfort, or perhaps a sign of worry for the impression he would give to the researcher. He also tried to describe his personality: a depressive person and a loner, who would get agitated and angry when conditions became more difficult than what he could manage. This is why at the beginning of his hospitalisation he just could not come to terms with leukaemia:

Once, once I, I got in here and I've got a bit better it was really hard to sort of come to terms with. You know a lot of it was, almost like in a dream world, you know it's like, "Is this really happening?", I'll, I'll just wake up and it's a bad dream, but – no ... **George**

From this extract it seems that the process of decay in the coping mechanisms can be affected by previously adopted coping styles, irrespective of them being successful or not. This sense of living in an unreal “*dream world*” was almost a sign of his difficulty to cope. This feeling of uncertainty is further explained at the subordinate theme ‘world of emotions’ (section 5.4.8). It is not uncommon for patients who undergo extreme stress to regress to maladaptive behaviour. In George’s case it is the use of an escaping strategy by choosing to self-medicate that is a clear sign of the decaying process.

5.4.4 Embodiment of leukaemia

Participants had to deal with a number of physical symptoms and treatment side effects. The physical impact of leukaemia was experienced through the process of decay due to the initial phase of the treatment being particularly challenging. Dealing with infections and fatigue were the most distressing side effects within patients’ accounts.

Robert, during his first treatment, caught an infection that prolonged his hospital stay from what normally would be four weeks to six. His description of receiving chemotherapy for the first time was very vivid:

I was in here for almost 6 weeks, em, the first 2 weeks was essentially with the chemotherapy then the next 3 weeks were getting hit with all of these aches and pains and problems, particularly with eh, a sort of lung fungus. I had colds and all these sort of, well as you know you get lots of you know, the resistance is very low, so anything coming along, colds, these, you get it, and I got quite a few and I just felt absolutely dreadful [...] The first time around I felt like death, you know, I just, I'd had enough and I felt

*absolutely dreadful. [...] But it was, it was bad, you know, it was for me, I felt absolutely ... I didn't want to know anybody, anything or, otherwise, I just wanted to sleep, cough, but that's about it, just staying alive, nothing else. But that, I, I think 'cause the function of the, the first course a lot of people feel the same as the, the cancer brought right down, then you've got zero em, to resistance so anything that's happening to come along, you get it and you just feel absolutely hellish, and I did. That was the worst I've ever felt. **Robert***

Robert described his experience of side effects from his chemotherapy treatment as “*being hit*” with pain, feeling “*dreadful*” and “*hellish*”. He is using a strong metaphor to describe the pain he has been through, both physical and emotional. Besides pain, he was also fatigued, and, as he mentions, all he wanted to do was sleep. There is a sign of resignation at this stage of the interview, as that was the first time he felt so weak and, in fact, it is at this point when for Robert, leukaemia became visible: through the side effects of his treatment. Even later on during the interview he used the phrase: “*feeling rotten the first time around*”. Rotting is one of the main processes of decay in nature, and it involves more than one human sense: vision, smell, taste and touch. As with other types of cancer, patients receiving chemotherapy for acute leukaemia feel that their body disintegrates gradually. Indeed, one of the main chemotherapy actions is cellular death, either by healthy cells or carcinogenic ones. In this instance decay takes up a literal dimension. The physical body dies at the cellular level in order to give space to the new healthy cells to mature.

It is worthwhile focussing on fatigue, to further demonstrate the level of decay. Participants explained how fatigue was the most distressing side effect from the treatment. Ian below is providing his experience of fatigue:

*I mean the one thing which has been worse than I had anticipated has been the fatigue which is an almost, is an added, I kind of understood tiredness before [...] It's kind of lying down and not feeling able, not feeling able to do anything you know to the extent that if I need to go to the toilet to brush my teeth it's been quite an effort to motivate myself to get up and do, and do so. And obviously the, the odd situation of kind of dozing off and almost imagine myself doing whatever needed to be done which, which doesn't help, which isn't a particularly effective way of then, of doing it [laughs] and then you know kind, kind of lying there doing that and over a period of time while the thing's still, it still remains undone. **Ian***

Ian experiences fatigue as having a major impact on his daily activities. He needs motivation to get up and get things done. He is describing this primary experience of fatigue and at the end he laughs. Again there is no other choice, and in his eyes there is no obvious way to deal with

this fatigue. The nature of fatigue in haematological malignancies is twofold: it can be both a symptom and a treatment side effect. As a component in the decay process, it originates from the physical domain and expands to the emotional and social.

Symptom experience played a significant part in participants' making-sense process of decay. At the beginning it took the form of hidden signs and later on it was the symptoms and side effects from the treatment that made leukaemia more real and visible in their eyes to understand.

5.4.5 The social world

As a restrictive cancer, acute leukaemia can have a ripple effect on patients' social world. Participants expressed worries regarding how their families would cope with the illness and expressed the level of acute leukaemia's impact on their interpersonal relationships. A social world in the process of decay can have different ramifications.

For example, Molly was 29 years old when she received her diagnosis. Her job involved speaking to members of the public on a daily basis. She provided an example of this decaying world:

*It's like after – you start thinking like, you more think about other people I think as well [like?]... like how other, like how your family and stuff, will affect them more, like you worry more about them than yourself I think [mmm] which is, you know and like your job and just everything that you do and like what you're affected kind of by, so ... it's ... it's weird. [...] different people I suppose would feel differently, I think if you worked for somebody, you know you'd just go, "Oh well, I'll see you when my treatment's finished," but when you work for yourself like, especially, 'cause I work with the public like I'm like, like I've had to phone all my customers and tell them what's going on, you know ... so that, that's quite hard because it's quite like ... it's almost embarrassing in a way to have to phone people and say I've, you know I've got leukaemia, 'cause they're like, "Oh my God," you know they're all like really shocked and, you know ... they don't know how, but, to react but it's something that you have to do, you know you're like. **Molly***

From the early days Molly started to think about the impact her illness had in her social life. She repeated how "weird" it was because she was still trying to make sense of her diagnosis. She felt a pressure from her social world that she called "embarrassment". In fact, informing her customers one by one and not through a face-to-face interaction that she had acute

leukaemia at a time when she herself had not come to terms with the news made her coping process more difficult. She had to face the reaction of her wider social circle in a time when she was not prepared for it. She admits that people were shocked by the news, yet she speaks about the illness as though it has happened to someone else.

Patients' interactions with their acquaintances can hinder their sense-making process by highlighting the gap between how they and their world conceptualise leukaemia. Patients' decaying social world can be of worse impact on their making-sense process when it includes persons from the close family. Towards the end of the interview, Molly described how her relationship with her boyfriend was affected by leukaemia:

Molly: *It's OK. Em ... I don't ... I suppose the relationship's kind of the same really there's no, but he's got his own issues to be honest [laughs] em he, he basically deals wi stuff by not dealing with it [laughs] so ...*

Constantina: *M-mmm, does this bother you?*

Molly: *Aye, of course it bothers me 'cause I'm totally the opposite, but there's nothing I can do about it now, I don't want to, like I don't have the energy to argue with him so I'm not going to do that, you know so, em ... you know he doesn't like to hear me say, "Oh, my hair's falling out," or whatever [...] He doesn't want to deal with it [...] you know so it's like, I don't really tell him much about how I feel about it because he doesn't want to deal with it so he can do his own thing and not ... I don't have, you know I'm not like if he can't deal with it, there's no point in me saying, "Oh, this is happening, this is happening, this is happening," because it's just going to make it worse [m-mmm], and it makes it more stressful [m-mmm] for me, so there's no point, so ... it's just ... getting on with it and not really having to think about it so ... you know ... I'll just leave him to it.*

Molly experienced a forced isolation. She made a claim at the beginning that her relationship with her boyfriend remained the same after her diagnosis. However, she was not entirely the same person: she was ill and her boyfriend chose not to see her as such. They had different coping styles; he was using negative coping (avoidance, denial), whereas she was using a more positive approach (social coping). Any effort to communicate symptoms or part of the illness to the partner, she found pointless and, in fact, increased her anxiety levels. Being in an unsupportive environment where illness is ignored, can further increase the magnitude of emotional isolation. The decay here is imposed in one sense through the different ways persons within a family cope and how their different strategies create obstacles in the meaning-making process of patients.

Emma was 62 when her AML relapsed. Her social world was in decay for many years, mainly by her choice. In the following extract she describes how she used to deal with her social acquaintances:

You don't, it really does make you think and also you find out who your real friends are [mmm] when you're poorly. [...] Well, we belong to a swimming club ... and eh, our F does the swimming and people that I thought, oh well I've never been over friendly wi anybody 'cause I just don't know why, I just keep back, but people I thought that were friends – they're not ... and yet some people that I wasn't too sure of have proved themselves that they are friends [...] 'cause I think my attitude, I, I tend to think, "Stay back," do you know and it does make you feel an outsider, but 'cause it's me [...] I'm very mistrusting with people. I don't know where that comes from ... **Emma**

Emma was a very private person who would, in most instances, mistrust people. Her social interactions were in decay for the most part of her life. Although in this extract there are signs of transformation in her attitude towards her social world, the signs of decay are still noticeable. She always kept her cards close to her chest, valuing trust in friends. However, she never had real support from them, at least to the level she would expect. During the second interview she made it clearer:

I always work them out first and usually if I don't like somebody, it turns out there's been a reason why I didn't like that person in the first place. You know and some of them will give the benefit of the doubt, but even then pffft, just something's just not, I mean I've set people, I know it's not very nice, but I've, I've set people up, you know people I've been unsure of, I've said things to them and then I've heard it from other people, it's come back to me and I think, yeah I was right [mmm] [...] then you think to yourself – "Nah, I didn't trust them wi much," but it's nice to have somebody, like years ago I used to have this friend, we used to always go out to this em, Folk Night and we used to sit there and just nag, have a good old whine and do you know, we were both single parents and we had a lovely ... you know and that was great that, do you know just doing that, but it's nice to have somebody you can speak to that you know is not going to go "gobbing" elsewhere, it's brilliant that, but there's no many but, everybody comes to me, but when I need anybody, there's never anybody there that I would basically trust. **Emma**

Mostly by choice, Emma was quite isolated as she valued confidentiality in her friendships. She describes how "nice" it would be to have someone with whom she could be truly open. It seems as if she desperately wanted to bring back in her life some aspects of that old friendship. Her role in her family – she had raised her three grandchildren – has always been the one who supports others. But, what happened when she was the one who needed

support? Her grandchildren had fallen below her expectations, as they were just “*males*” as she mentioned during her interviews. This derives from a social construct that the act of caring is tied with women rather than men. Through the years Emma became more sceptical regarding others and occasionally she even suspected people’s mistrust.

During the initial phase of patients’ illness their social world is in decay depending on how they dealt with it previously. Living in a shrinking social world mainly because of leukaemia’s physical restrictions, can create feelings of alienation that can complicate patients’ sense-making process.

5.4.6 The self

Another aspect of the process of decay was how patients viewed their self. Two subthemes were identified: blaming the self and the impaired self.

Patients, in order to make sense of their leukaemia, want to attribute a cause to their illness. It is not uncommon to resort to self-blame as George does below:

*I've been a heavy smoker for 25 years, 30 years, and my first thought was [claps hands together] - “I've been caught,” [mmm] you know I, I know the dangers of like smoking, you know smoking’s related to sort of disease and I, I'd sort of just initially thought well it's my own fault, you know I, I know the risks, “I've got cancer now”, but as it turns out they don't think that leukaemia has got any relation to, to smoking diseases so, but ... it was, it was a bit of a shock. **George***

This self-blame is part of the explanation/offering a cause for leukaemia. George at the very beginning blamed himself – “*I've been caught*”, “*it's my fault*”; it was the old self of bad habits (smoking) that led to this life-threatening condition.

Another sign of decay in the self would be in the disabilities of the new impaired self. Mary’s childhood leukaemia relapsed when she had just passed her fifth year as a survivor. Below she describes how frustrating the ill version of her self is:

I like to be busy and I like to have things to do, and I just have to bring it down a notch because I get tired quite quickly and, so yeah, and I don't like how that, you know like my mind's still going but you know my body can't keep up with it so it, that, I struggle with that a little bit and because eh the chemo kind of attacks my fingers, you know like it, it gets and I get a bit shaky but I can't really draw which would be the thing that I would do

if I was just sitting at home, so then I get frustrated that it doesn't look like something that I could have drawn before, so there's a bit of frustration ... I try and do it anyway but it's a bit, it can be a bit squiggly and stuff but ... yeah, I just get, I just get a bit frustrated with it sometimes, but I should learn to love the squiggly drawings that I do [laughs].

Mary

This ill self has fewer capabilities compared to the previous, healthy one. She cannot complete tasks anymore (i.e. drawing) because she is suffering from the neurotoxicity of her chemotherapy regime. However, this ill self still carries her fully functioning mind and spirit; the ill body carries a healthy mind. This is why she ends up saying that she needs to learn to love her new ill self. This will start by accommodating her “squiggly” imperfect drawings.

Similarly to Mary, Kevin, in the following extract, explains why he did not feel like himself when he went to the cinema:

*Even being in the pictures, and I had a jumper on that I used to wear and that, and I really felt quite uncomfortable, so although I don't mind, I don't care what other people are thinking, myself I feel quite uncomfortable wi' the, wi' the, the size I was and the shaved head and things but em, I suppose it was quite strange to, to, to worry about yourself and not other people but it just, it just felt ... **Kevin***

Kevin describes how this altered version of his self, ‘the ill self’, affected how he felt within this social environment. Being surrounded by people who did not actually know him, he felt like he was wearing somebody else’s costume: although he was wearing his own jumper, his physical body was different: bigger and hair-less. Perhaps, he only became aware of his altered self when he went to the cinema through that strange emotion. He is voicing the fact that he does not care about what other people will think of him.

As part of decay, the ill self is one that physically does not look like the old and emotionally can bring a sense of alienation. It is then when patients start to question who they are, whether their core self remains the same as before the illness. This sort of dialectic that occurs in patients has its roots in the process of decay, as the physical decay leads to an emotional decay and then it can move towards transformation.

5.4.7 Counting losses

An important part of decay was loss. Acute leukaemia, like other types of cancer, was understood through the various types of loss it posed to the person. Participants in the study identified a number of losses that leukaemia had brought into their lives. These were loss of normality, loss of control, loss of independence, and loss of future.

For instance, Ian understood leukaemia through loss:

*I guess a sense of loss without anything conc-, without a kind of being tied in anything concrete [...] I mean it's not great to suddenly be able to do a lot less than normal and almost struggling to think straight for parts of it, for part of the time as being odd and quite unpleasant and also the restrictions put on me as part of the treatment have been unpleasant to me, being stuck in the ward for long periods and also obviously you lose a lot of the control and activity that we normally, we normally have [...] Basically, I had other, other ... it sounds daft but I, I had other things planned, do you know what ... I was at a point when I was looking to get a better contract sorted out at work, thinking of settling down a bit more in, settling down a bit [...] and suddenly things have all been, they've all been quite, they've all been quite up in the air, and also I, I suffer a bit of, I suffered from some back pain, I've been lucky enough to be quite healthy all my life so that, there's nothing particularly to suggest I should have been, that I might have been, at all likely to get it at this, at this, at this point in my life. **Ian***

Ian was desperate in this extract; there was a general sense of loss that he could not describe precisely. It was the loss of future and the loss of a certain world that became more apparent to him. Then, as the interview progressed, there were references to loss of normality, loss of independence, loss of control, loss of the sense of freedom. Patients' understanding of acute leukaemia through counting the different losses is a component of the decay process. They go through a grieving process of what was lost, their previously normal life, their freedom, their future plans.

Andy was diagnosed with APML, a subtype of acute myeloid leukaemia that is potentially curable. Of all the participants interviewed in the study, Andy alone was the one to have a cause for his leukaemia. As mentioned in section 5.2, several years ago, he was treated with a chemotherapy agent proven to treat MS and leukaemia, but which is also responsible for causing leukaemia. In the extract below he describes the loss of control that acute leukaemia has brought into his life:

*I, I felt pretty sick, eh, but you know – “what do you do?” in a situation where your control of the situation is “nil”, you have no control, and actually you put your faith in Dr [name] and his staff, who have been excellent by the way, and you're actually putting your faith in them as professional doctors. **Andy***

In this extract he is stressing the loss of control by using the word “nil”. In fact this loss of control over acute leukaemia leads to an unconditional surrendering of the patient to the healthcare professional team. Patients, when diagnosed with acute leukaemia, need to be admitted to hospital as soon as possible. Since they do not have the expertise, and because they are in a phase of crisis, they have to rely on clinicians’ advice. Once there, they need to abide by the new rules of a new unknown environment, the hospital.

It comes as no surprise that the meaning of acute leukaemia has various aspects of loss encased in it. In this sense, decay is about patients realising the impact of acute leukaemia by counting, and, in a way, grieving for what was lost.

5.4.8 World of emotions

Participants expressed an array of emotions during the interviews. In the initial phase the shock of diagnosis and fear dominated their minds; this was followed by uncertainty and a sense of living in an unreal world. Other emotions included feelings of guilt, embarrassment, depression and loneliness. These emotional responses were signs of their decaying emotional world.

During the first period of being diagnosed, patients described that they were in a state of shock. Stephen, in this extract, mentions that the diagnosis of leukaemia was a “*shock to the system*”:

Going from thinking that I had glandular fever or a virus to find out you had cancer was a bit of a shock to the system. Em, like that’s still even hard now to think that I’ve actually got it, it’s not something you expect to have sort oh when you’re my age. Obviously you hear about it and that but you don’t expect it to happen to you. [...] it’s just, especially at this age, that’s what I feel like you might get it, but for some reason, I suppose there’s no age limit like you get it at, but I just never would have thought that, ‘cause I mean like I’m never sick really, I’m, like keep myself fit, young, so just, I wouldn’t have thought it, but ... obviously, it just shows it can happen to anyone [...] I, I know I started crying [laughs] ... right away, em [...] but I know like that took me by, it was like a big shock and

*I got quite emotional [m-mmm], about it at the time for a probably a few, even now it feels quite difficult to see that [yeah], to feel like I've got. **Stephen***

The “system” Stephen is referring to can have a dual meaning. Firstly, he may be referring to the systems of the human body. In the human anatomy, the body is made of ten different systems (i.e. skeletal, muscular, nervous, respiratory, cardiovascular, lymphatic, endocrine, digestive, urinary and reproductive). These systems need to work in tandem and be coordinated by other systems to form a living and healthy human body. In the case of one of these systems being damaged, the human body becomes unstable and may ultimately die.

A second interpretation of the “system” is that of beliefs. Stephen was only 21 when he got his diagnosis and he kept a healthy lifestyle including exercising, a healthy diet and no smoking. For him, cancer was linked to old age, to smoking and to lack of exercise, whereas youth had the element of invincibility. His diagnosis was not something he would expect to happen, therefore when the news was announced it provoked a very emotional response. In this extract he also describes the feeling of an unreal world as it is hard for him to think that he has leukaemia. Of note is the fact that when Stephen talks about acute leukaemia he avoids the use of the actual word ‘leukaemia’; instead he uses the pronoun ‘it’. He is distancing himself from his diagnosis of leukaemia.

Patients’ making-sense process starts the moment they are informed of the news of their diagnosis. Shock as an emotional response is a sign of decay, one that patients need to overcome. The sense of the unreal is also common when someone receives a cancer diagnosis. Perhaps, due to acute leukaemia’s primary invisibility, the shock is experienced to a greater extent. Subsequently, great shock may hinder patients’ efforts to understand their illness and may slow down the initiation of coping mechanisms.

George described this sense of the unreal as being in a “dream world” below:

*Once, once I, I got in here and I've got a bit better it was really hard to sort of come to terms with. You know a lot of it was, almost like in a dream world, you know it's like, “Is this really happening?” I'll, I'll just wake up and it's a bad dream, but – no ... **George***

What is striking here is how George is questioning whether leukaemia is happening for real. This sense of living in an unreal world can be increased due to leukaemia’s fast track characteristic. Once patients receive their acute leukaemia diagnosis, treatment needs to begin as soon as possible. Patients are left with a sense of numbness, wondering ‘did this really happen?’ as they do not have the luxury of time to absorb the news.

Similarly, Ian explains this sense of living in an unreal world; as though acute leukaemia was happening to somebody else:

*I seemed to, it seemed to be a bit unreal in the sense at least I managed to pick an infection ... I suppose the odd, you know the odd sense of having quite a lot taken, taken away based on something which wasn't, kind of readily apparent to me, so I guess a sense of, a sense of loss without anything, a kind of being tied in anything concrete ... **lan***

This sense of loss he refers to is like an invisible evil (acute leukaemia) lingering in the shadows. Ian's distress is evident through his repetitions of the word "taken": the illness came to steal, to violate his notion of security and certainty. Indeed, a lot was taken away from him: the control over his life, his independency, his future. This sense of unreal is what makes it more difficult for him to understand leukaemia.

Furthermore, acute leukaemia provoked additional emotional responses. Molly below describes her unusual sense of guilt and embarrassment stemming from her sense of responsibility towards her social world:

Molly: ... or how long I was going to be off for so, I've had to kind of like phone all them and leave people messages [laughs] and kinda just, you know it's, like 'cause some, I mean like some, some of my clients I've known for like about 8 years, so it's a long time you know they, you feel as if you, you do know them and they know you so you kinda owe them that, that you would let them know what was going on so, that was kinda hard and I feel guilt as well for not being there. It's kinda like ... it's, it's harder that way because like I feel as if I should be there, you know. It's, it's a strange feeling actually ...

Constantina: You feel guilty and you felt embarrassed as well

Molly: Yeah I, because you're like, mmm, you know I'm not here because of this but then you feel as if, like I feel as if I should be there because I've always been there, you know, like you just like you do. I think you do think more about everybody else sometimes than yourself so ...

Molly felt she owed people the truth; she always had an honest relationship with them until she received her acute leukaemia diagnosis, so once more she had to be open with them even with such sad news. She is stressed that she 'had to' let them know, indicating an inner urge that she understood as a moral obligation. At the same time, she seems to struggle to find the word to explain why she had this urge. She herself was trying to understand her emotions as well. Her illness had an impact on her roles and daily activities that led to augmenting her feelings of guilt, another sign of the decay process.

Bruce, a 72-year-old man diagnosed with AML being in a hospital isolation room felt very much like being in a cell. His sense of loneliness penetrates the text:

But I'm isolated [...] they put me into a, a room on my own at the end [m-mmm], and that made it worse because when I was in wi' the fo-, the other 3 guys, I was speaking to somebody, but when they pit yae intae a room on your own, and you've naebody to speak to and you're just looking at the TV it drives you up the wall, if you get my meaning. You can read the paper, you can read books or whatever, but lonesome, ken I'm never, I, ken I've never been on my own. My wife came in to see me and doctors and nurses, but you, you're walking, yae, yae, ken just walking roond that bed, but, I could'nae explain it, it was just horrible. 'Cause yae, yae like to walk aboot and get motivated [mmm], ken speaking tae folk, but I was so [sounds emotional] fed up and lonely, ken. [...]I knew that eh 3, 4 days on your own, you're crawling up the wa' yae ken.

Bruce

Bruce is using a strong metaphor to describe the emotional impact of his imprisonment; it made him “*crawl*” up the wall. His agony is prevalent: he feels like a trapped insect that tries to find its way out by crawling up the walls of confinement to freedom. Leukaemia places physical restrictions to patients resulting in increased feelings of isolation and loneliness. These are suggestive of decay at an emotional level that can prohibit patients’ sense-making process.

The process of decay as it was presented reveals the complexity of the various elements that seem to happen at the same time, based on the participants’ experience of acute leukaemia. For instance, a decaying social world can have an impact on a person’s emotional world and subsequently on their coping strategies. However, the presence of this process was significant in order for transformation and, later, growth to happen.

5.5 Transformation

Transformation refers to the shift from one process (decay) to another (growth). Similar to decay, this major process included a range of subordinate themes: leukaemia in disguise, a holiday in prison, coping with leukaemia, embodiment of leukaemia, the social world, the self, counting losses, and assimilating leukaemia. Compared with the other two processes,

transformation is more inconstant; therefore, it was not always clearly demonstrated. In the extracts that support each subordinate theme, transformation can swing either towards decay or growth, but it is exactly this middle state of change that transformation refers to.

5.5.1 Leukaemia in disguise

Within the process of transformation leukaemia's form begins to evolve. Patients start to perceive their leukaemia more as an individual illness; they form mental images of what their cancer looks like. At the same time, the difficulty in making sense of leukaemia remains. Familiarising themselves with the medical terminology is also an important part of their sense-making process within transformation.

For participants in the study the transformation process began when they started to put a face to their previously invisible illness. Mary, artistic in her nature, gave a vivid description:

Mary: *I think if it was to have a landscape it would be like, it would have thorny bits in it [m-mmm], eh just ...*

Constantina: *Like a field?*

Mary: *Yeah, yeah. Em, getting prickled every so often [mmm], em I don't, I think eh, if I was to relate it to the sort of masks, I think masks is quite good as well 'cause, I don't know, I think you almost wear a mask with the sort of bald look that, you know you go for the sick look and you do all kind of look the same, well you don't, well you don't 'cause you've still got your faces but, you're all kind of bald heads, a sea of bald heads. Em, could have a pebbled beach then with bald heads, couldn't you? Sort of shiny [laughs] ... I don't know. Eh, yeah I like, I like the idea of a mask, you do kind of wear the sort of "sick" mask if you, you know 'cause if I walk down the street people, you know without a hat on, people [...] know, m-mmm [mmm], so I suppose you do kind of wear this mask that, and it's quite a, it's quite easy to hide behind the bald head 'cause people sort of see that first, unless I've done my eyes obviously and people see that [laughs].*

Mary was in her final year of her studies in arts when she was diagnosed and her final assignment involved drawing masks. Initially, she pictured leukaemia as a field with thorns that pierce her body. This "getting prickled" can have a triple meaning here. Firstly, literally, she can be referring to the tests she had to undergo as a patient, to the needles that went through her body during intra-venous catheterisations and bone marrow aspirations. For patients with acute leukaemia, giving blood samples on a daily basis is a routine practice, while bone

marrow aspiration is usually done at specific time-points to check the bone marrow activity for the effectiveness of chemotherapy. Secondly, she can be referring to the physical distress the illness causes. This can be a constant reminder of leukaemia being there. Thirdly, because she had leukaemia twice, these thorns can represent the instances of leukaemia. She wanted to move on with her life but leukaemia came back, 'prickling' her again.

Transformation, as already mentioned, is a fluctuating process where things change. Mary is still processing leukaemia; she goes on with two equally strong metaphors: the mask and the sea of bald heads. In her description there is a double masking: the bald mask that covers the true self and a second masking that she employs by wearing a hat and colouring her eyes in order to conceal her baldness. There are projections to the subordinate theme regarding 'the self' here: the illness is masking her true self, giving her a bald face, an illusion of an altered self. She then tries to camouflage it in an effort to prove that she is still the same person.

The third picture Mary mentions, the "*sea of bald heads*", is perhaps referring to all patients with leukaemia. During the interviews she mentioned how surprised she was when she was first admitted in hospital, to find out that leukaemia was not as uncommon as she thought it would be. This was her way of expressing how many people, adults and children affected by leukaemia and cancer, all have eventually the same bald head. She stressed how they all look *the same*; they are all passengers on the same train, on the same journey of cancer. They became all *patients*; the bald head has stripped them of their previous identity and defined their new identity.

Either seen as a field, or a mask, or a sea of baldness, acute leukaemia is not faceless anymore; its disguise has started to crumble. This transformation from an illness being in disguise to an illness with a more specific shape indicates how patients begin to create specific meanings of their leukaemia.

Interestingly, the process of transformation can take an unexpected turn. For example, Kevin's initial explanation of leukaemia progressing was somewhat confused. In the extract below he describes how leukaemia differs from other types of cancer:

...It could spread anywhere and [m-mmm], and they could get more complications wi that, whereas in my bone marrow it's, it's, it's stuck in my bone marrow, so it, it can't really get out and spread wild, so ... I don't think I'm going to have to worry about, you know some people could get some news about it, that, that they're cancer's going away somewhere but it's spread to their, wherever [...] whereas as far as I've been aware there's not much chance of my leukaemia, it, it's confined to, to the bone marrow, and

although that's serious enough it's not going to get out and cause mayhem all over my body kind of thing [mmm], em ... so maybe that's, maybe that's a good thing, maybe it's a bad thing, I, I don't know. But when they start, I think it's, the word, you know "bones", cancer in your bones and, that's quite scary, em obviously 'cause that's a terminal illness but they haven't mentioned, they haven't mentioned that, yet anyway. Kevin

Kevin had mixed different information with general knowledge to form his initial understanding of leukaemia. He conceived it to be beneficial that leukaemic cells overrun normal cells in the bone marrow. Compared to other types of cancer, for him the marrow was a safe 'cage' that confined leukaemia in one place, preventing it from spreading to the rest of the body. His understanding of leukaemia transformed in an unexpected way: he combined some of the information regarding leukaemia with his pre-existing knowledge to create an interpretation that served his purpose at the time. This kept him hopeful and positive. Supporting the notion that transformation is ever-changing, later on his understanding moved on to a more consistent and accurate perception of how leukaemia was initiated:

I, I do tell them just a bit about my understanding of it, which is not great em, the only, the only thing I know about the leukaemia is that it, it's a, a, a quick acting cancer [m-mmm], which just overpowered my immune system. Em I actually learned that a lot of people fight leukaemia off themselves, em your own body, your own immune system can deal with it, but mine came on so quickly that it didn't and then it starts [...] mine just came on too quickly and overpowered, em, and my white blood cells stopped during and stopped going out and, and then eventually the leukaemia kills them. Kevin

In this extract there are signs of Kevin's transformation moving towards growth. His understanding of leukaemia reformed to being the result of an imbalance between the immune system and the developing cancerous cells. The transformation process in his understanding moved from disguise, to a caged marrow, and eventually, to a state of imbalance.

Although an unstable process, transformation is essential for patients in order to make sense of acute leukaemia. Acute leukaemia from initially being invisible, or disguised with infection, begins to take shape into a more tangible illness.

5.5.2 A holiday in prison

Patients' perception of imprisonment transforms as well. As time passes they seem to get used to the idea that their hospitalisation is only temporary and for a reason. They begin to familiarise themselves with the previously unknown hospital environment. A new routine is emerging that involves aspects of their new life in the hospital (i.e. treatment, socialising with other patients and hospital staff).

Patients emphasised the importance of breaking the hospital routine to go back to their homes in the interviews. This is what made their stay more tolerable and subsequently helped them come to terms with their diagnosis. Between the two interviews, George was able to go home for a week. He describes how important this was for him in the following extract:

*... 'cause you're in a sort of sterile environment here eh so that was good and then just the fact that I could go home, relax, basically do what I want to do ... Yeah. I mean I, I couldn't do everything I wanted to do because obviously my strength is, is all gone, you know so even walking to the shops was a bit of a struggle but even that it, it was good just, 'cause I can go out and do it for myself, eh, so yeah it was great, great [...] it's something you strive for here, it's a little "goal" you go for you know, 'cause you, you know you're going to be in here for months and months so any chance oh even getting a day or a couple oh days is having a goal that you're trying to, to, to go for, you know, so, yes I can'nae wait for the next time [laughs]. **George***

As the treatment progresses, patients have some limited time at home that seems to be of vital importance. George had the opportunity to go from a "sterile", almost hostile environment, because of the restrictions posed by the leukaemia, back to his home, his sanctuary. He was free again; he could make his own decisions. The transformation of the state of imprisonment takes place when he begins to withstand, to have this little "goal" for the time of his hospitalisation. In George's eyes this "goal" takes the meaning of great personal achievement, bringing him closer to health and life. Offering the chance to patients to go home to a familiar environment is an important element that seems to help their process of making sense. They need to break the treatment and hospital routine, and return to their previous state of normality. This can offer them the space and time to adjust, an element that was taken away at the beginning of their acute leukaemia journey.

Transformation, however, was not always easily achieved; patients could regress to decay. Ian, for instance, found very difficult to get used to the new hospital environment:

*Well, I mean when I was at home I was able, obviously could afford what I took myself and organise that but coming in here you're really, basically dependent on other people not messing up in order to get the correct medication and with things like, with, with things like line care and so on, dependent on, and with the, with risk of infection, dependent on other people, you're basically ... basically rely on other people following correct procedures and so forth in order to avoid getting quite, really what can be quite nasty problems. **Ian***

For Ian, what seemed particularly difficult to accept was that he had to rely on other people, in this case the healthcare professionals, in order for his health condition to improve. The break he had from the treatment while at home indicated that he could be in control of his medication, whereas this control decreased to a minimal level when he was at the hospital. It is striking that he could “afford” to organise his medication intake providing a strong contradiction with his situation during his hospitalisation. Also, in this extract there are signs of growth in terms of his becoming an expert (“central line”, risk of infection”). At the same time, the transformation seems to move back to decay, as he disapproves of the fact that there is no other choice but to depend on clinicians. There is a clear negative attribute in his use of the word “rely” to describe this dependence, signifying his inner struggle with losing control and at the same time judging clinician’s authoritative nature.

Contrary to the rest of the patients in the study, Emma saw her hospitalisation under a different light:

*This in here, you're cocooned in that bedroom on your own, although you're allowed to leave the doors open now which makes a huge difference I must say, 'cause before they used to shut the door and you were in there, now the doors are left open ... But yeah that, that, that, that's what it makes you feel like it's once you get home – that's when reality actually hits you. **Emma***

Emma found her time being in the hospital as if she was inside a cocoon. The metaphor she chose to use, the cocoon, is one of the most typical examples of transformation in nature. It is the protective casing that enables the chrysalis to metamorphose into a butterfly. The cocoon here is the hospital room, despite its confining and restricting nature, it also offers a shield of protection. Within the cocoon, all physiological things transform: she is receiving the treatment that transforms her marrow, leukaemic cells are killed and new cells are generated. The hospital cocoon may also provide protection from her emotional response. However, this transformation is not stable, it swings back to decay, once she gets back to her home.

Emma and Ian are examples of the degree to which transformation of the sense of captivity is a changeable yet paramount process in patients' efforts to make sense of acute leukaemia.

5.5.3 Coping with leukaemia

Patients' coping strategies can transform in order to adjust to acute leukaemia. By using old frames of reference, they compare and contrast their illness experience with previous difficult situations and can choose to change their strategies if they deem them to be unsuccessful.

On many occasions, participants in the study appraised their previous coping strategies as ineffective; therefore, transformation was needed to accommodate the new reality of leukaemia. George mentions below how he made a rather conscious effort to change his previously negative, pessimistic attitude to a more positive one through reading and self-suggestion:

*I've always been a sort of depressive [mmm] pessimistic person, I think it's an Aberdonian trait to be quite honest, living in a grey sort of city. But em, I mean I, I've read up about things like this before [m-mmm], eh, you know I've got a thirst for knowledge, even if it doesn't directly affect me or anything and you know one of the things I have been aware of is having a positive attitude can, you know using your brain to actually control, or maybe not control, but to help change eh the way your body works [m-mmm] em and I thought, yeah a positive attitude just [sighs] is it having a "faith"? - I don't know, 'cause I'm not a religious person but just believing that I am going to get better, therefore I will get better [...] Em which is, like I say because I'm such a pessimist it was quite hard but I realised once I was in here I needed to do that, 'cause I, if I was going to stay here and just go ... mump and moan about ... "Oh, I'm going to die ... ", or, "This is not going to work ...," it would have a negative effect on the treatment I believe [mmm], so that's why I'm just, I try to be you know happy and, if anything goes wrong, well, it'll get better the next time round. **George***

George's transformed coping strategy moves towards growth in this extract. It is still noticeable how he made this conscious decision to change his coping. He searched his knowledge database and selected to use information on how positive attitude and self-suggestion affects the physiological responses of the human body. This transformation has helped him deal with any possible setbacks he faced during his treatment. Patients can consciously opt to change their coping mechanism in order to facilitate their making-sense process.

Additionally, patients with acute leukaemia utilised comparing and contrasting of the current situation with previous difficult times in their lifespan. This enabled them to see how they coped previously and decide whether or not to act similarly. Bruce offers one such description:

*But here's me 72, I was just thinking how lucky I wis, ken, I even though I had had a bypass and how happy I've been within, because more or less when you ha'e a bypass you say, "well nothing else could happen tae yae", but then again "klonk" somebody hit me over the heed wi' this [laughs] ... and it's, that's, that's put the icing on the cake that stopped me right me tracks [laughs], but I'm getting, I'm getting to terms wi' it, that's a' I can say [mmm]. **Bruce***

In this extract Bruce is comparing the two instances in his life when his health had been threatened: once with the heart surgery and now in facing acute leukaemia. He is undergoing an appraising process through comparing and contrasting his two illnesses. He had falsely assumed that having one serious illness (heart failure) was the only thing that could happen to him. Unfortunately, leukaemia came out of the blue and it was during his second interview that he started to come to terms with it. The process of transformation here is moving towards growth. For patients having time to think and reflect was an important part of their sense-making process.

5.5.4 Embodiment of leukaemia

The physical impact of leukaemia, including illness-related symptoms and treatment side effects, is subject to transformation as well. As time passes, patients' physical status starts to improve.

Stephen's transformation process began soon after he started his treatment:

*Yeah, well basically, once my, once my counts started, they started giving me platelets and all that and ... my counts went up and then once I'd got this in and it had, like that I was sore for a few days and difficult to sleep and stuff and difficult, em to move about at times, but once it had healed up, like right, when you weren't getting your needles stuck in you and I'd been feeling, my virus had gone away, or whatever it was, em, my sore throat had gone, I started eating again [mmm], had more energy about me and I was feeling ... and the initial shock, it had kinda sunk in a wee bit as well [mmm], so I think all these things, as much as it happened so quick, once they started to go away em, it was easier to take. **Stephen***

The initial period of hospitalisation was more challenging to cope with because his body was in decay; yet, slowly his symptoms started to “*heal*”, to transform after his chemotherapy started. It is of interest to see how Stephen connects his physical transformation – which is the work of the treatment and supportive care – with his emotional transformation. Patients with acute leukaemia also receive supportive care as part of their treatment (i.e. blood transfusions, haemopoietic growth factors and prophylactic antibiotics) to counteract the side effects of chemotherapy. These treatments justify the transformation that occurs at the physical level. For the emotional level to transform there are two contributing factors: time and physical transformation. Time creates the space a person requires to adjust to the illness, and certainly the improvement of physical status helps in shifting the focus more internally, to the emotions.

The transformation of the embodiment of leukaemia contributes to patients’ process of understanding acute leukaemia.

5.5.5 The social world

Patients’ social worlds are in a constant change from decay to transformation and over to growth. Acute leukaemia can affect the previous roles they had in life, and can transform the balance of their interpersonal relationships. This transformation, in turn, can have an impact on patients’ processes to understand leukaemia.

Participants in the study stressed how their ever-changing social world affected them on numerous occasions. Mary describes how things were different this time when her ALL relapsed:

I feel very grown up em [laughs] ... yeah and I'm the adult and I have to listen to the doctors and it's me that reports back to the parents and, yeah no it is different being married and I have Roy now, and ... even, he's, even though he's a really good support I have somebody else to worry ... a-about, do you know like, I don't know because you see loved ones look at you and you can tell that, you know they're upset that you're unwell so yeah I have another one, another person that's so close to me that can see that and I suppose that's a difficult part about having him be, it's also, it's also nice to have him, he can keep me company in the hospital [laughs] and entertain me, so yeah, no it is different being married [mmm], and having him [...] My family is used, you know has gotten back in the way of being used to like the hospital visits and stuff like that, we've, we've slid back into it quite easily and we were, we were quite good of about just adopting a different way of doing thing, you know like, “Oh, Mary needs to go into

*hospital, so we'll just change the day slightly," [mmm] and eh, I have a sister and she's really good at just sort of adopting, you know just kind of, OK, we'll just change the day slightly but we'll still, still have it but just in a different way, so I feel OK about it. I would rather not be but if I had to be [mmm] em we would make it, I know that my family's quite good at making it work so I'm not that worried about it [laughs]. **Mary***

Mary was a married adult when her leukaemia relapsed. She accentuated how adulthood made her more responsible in many ways. What is striking though is how she feels about her husband, Roy. She considers him an extra source of support and at the same time, he is an extra source of worry. The transformation occurs on two levels: one is to accommodate the existence of a husband in her life with acute leukaemia. A second level of transformation refers to all the practical changes she and her family had to make in order to live with the different routine of hospital visits. Had it not been her primary experience of acute leukaemia to transform her social world, her making-sense process could have been thwarted.

Patients in the study often spoke of the transformation in their social world as a shift in the previous state of balance. Ian below explains how leukaemia changed the balance in his social interactions:

*I guess the balance of things is, of things has shifted. I mean ... well when I'm in here it's a case of people deciding whether they, whether to visit or not rather than [...] arranging, we'd either meet, either be meet in the office or arrange a time when we both want to ... when we both want to ... to visit. **Ian***

Ian found that the illness caused a state of imbalance in his social life; either he is referring to his family or his friends. Ian was not the most social of people; he would always plan ahead his social interactions in an attempt to control anything under his power. Leukaemia took away this level of control, because he was forced to spend time in the hospital, a place with its own rules and conditions. Certainly, he disliked the fact that he had to meet anyone who turned up during the hospital visiting times. Again, in his extract, transformation is not very prominent, rather it shifts to decay.

Patients can perceive acute leukaemia as a major factor affecting their social world. In order to find a new balance, where leukaemia is accommodated in their life, they need to transform the way they react, and interact with their social environment.

Another example of this transformation of the patient towards the social world is provided in Molly's account. Molly was very worried about how her social circle would react when breaking the news of her diagnosis. During the interviews her views started to transform by

dividing her social world in three parts: the close family, the friends and the acquaintances. Below she describes how her friends and acquaintances would react to the news:

*I suppose they're [friends], I'm not shocked 'cause I know what I look like but I suppose they're kind of a little bit more shocked thinking that ... "Oh, what's she going to look like?" you know, because if they haven't seen you, then they're maybe going to think that you're going to look really different ... and you don't [laughs], so they're like, "Oh, ... you just look the same." [laughs] OK, so, it's quite funny. And then there's people that you don't necessarily know that well and like that'll say something and they don't know that you're ill and what they say you can't, you've got, because of what they say to you, you've got to tell them, you know [laughs] [mmm] and they're like, "O-h G-o-d ...," you know and it's because you don't look ill and they're really shocked, so that can be quite, quite weird, yeah. **Molly***

Molly was still trying to make sense of what was happening. She found all these social interactions “weird” and “funny”. She felt urged to announce to people her diagnosis in an attempt to stop them from making assumptions and misjudgements. Because her appearance did not collide with what people would presume a patient with leukaemia would have, she went on to inform them bluntly. Either she was asking for their understanding or she wanted to be treated in a different way, like a *patient*. Or, perhaps, this was her way of proving to others that she was still the same person after acute leukaemia as her way to build up her confidence. Her views towards her social world were undergoing a constant transformation process. She had to find a way in which she would be able to interact with her world with minimal disruption in her sense-making.

The process of transformation significantly affected participants’ interactions with their social world. Again, due to its non-stable nature, transformation in this subordinate theme either swung back to decay or carried elements of growth.

5.5.6 The self

In this subordinate theme, transformation occurred more subtly. Patients with acute leukaemia may realise that there are changes in their self. They guide their focus towards preserving their old version of self and quite often they compare their old self with the altered version of self that leukaemia has created.

Participants in the study did not always notice how this transformation of the self occurred. Kevin's account is notable:

I mean it, it was dinner time and they were aw speaking about the job they were just doing, and they j-, they were aw moaning about the job they were going away to do, the likes o', you're joking, moaning, I would do anything to go away and do what you are away to do just now, so I really can't wait to get back, and plus just having a laugh wi' aw them it was, it felt like comfy again, it felt like I was, and I can't wait to go back.

Kevin

In the above extract Kevin describes how important it was for him to go back to his previous life with his friends and colleagues from work. He is striving to get back to the previous state of normality. However, what is really striking here is that being with his colleagues again, discussing trivial issues, gave him a sense of comfort: "it felt like *I was*". The sense of normality is entwined with the sense of self here. Just for an instance, Kevin felt like he was before the acute leukaemia; he felt normal and ordinary. Thus, the ill, not normal, alien self, vanished for a moment when he was with his colleague friends. His transformation worked in both directions here: from the normal, old self, to the altered, ill self and back to the old again for a moment. Kevin does not seem to be aware of this transformation, indicating that a subconscious process is taking place. Acute leukaemia might bring a number of changes to the core self of a person through an underlying process that patients are not always aware of. Nevertheless, either occurring on a subconscious or on a conscious level, this transformation of the self can impact on how patients make sense of their illness.

In the following extract, Emma is more aware of how her acute leukaemia has transformed her self:

*Yeah, yeah, oh it's, yeah it has, you know, now I'm more, yeah I think more of people now, well it's people that I, I know [...] that I should [yeah] you know. Yeah it's eh, yeah it does make me see these people in a different light. So I won't doubt their friendship, whereas before I thought, "Yeah, what do you want?" [laughs] do you know just to ... yeah that's, that's my, or that was my attitude, do you know what I mean? But, yeah, it makes me feel better. **Emma***

In this extract, transformation of the self seems to move towards growth. Emma always used to be a private person; her leukaemia had opened her to the world. Her personality characteristics implied a person that would always hold back in her social interactions. Now, she seemed to be more relaxed, less suspicious. She began to transform to a better version of her old self: one that would seek, accept and enjoy the help of people around her. Aside from

the references of her social world here, what is important is how *she* changed towards her social world. This transformation was caused by her leukaemia, perhaps because at this stage she was feeling more vulnerable and she was left with no other choice.

The transformation process in this subordinate theme is indicative of an inner process which patients may follow in order to make sense how acute leukaemia affects them as persons. This, of course, is not necessarily happening consciously and can move either way towards decay or growth.

5.5.7 Counting losses

All efforts to maintain normality and to replace uncertainty with some level of certainty and control in patients' lives are part of a transformation process. For the study's participants this transformation process seemed to be an integral component of making sense of acute leukaemia. Their focus was equally guided towards maintaining their normality and regaining control.

Molly, during the interviews, kept referring to her living a "semi-normal" life:

Molly: *Yeah like now that I'm out, like never having been ill, you kinda think that you can do everything like you would normally do - but you can't you know. You think you can like in your head because you're the same person, you think you can do everything normally but you can't, you know, so you've got to try and work round that [...] No, there's nothing that I used to do that I can't do, you're more tired so [mmm], so you don't have as much energy to be busy all the time as well, and then obviously I'm here so that takes up time [mmm] [laughs] you know, you've got to come and be here, so, no I don't, there's nothing that specifically that I us-, you know there, there's nothing specifically that I did that I can't do that, like obviously I can't work full-time and I can't you know, do that so. And just you get tired more easily I think as well [mmm], so ... whereas before I'd be like, "Alright, I'll do this and I'll do this, and I'll do this," but now it's like, right I'll do this and I'll see if I've still got the energy to do the next thing [laughs] so ...*

Constantina: *Does this bother you?*

Molly: *E-m, it doesn't really bother me as much, 'cause I know why, it's not like it's ... a permanent, you know it's not like it's forever, you know it's, it's got a reason [mmm], so [slight pause] I think as well like because other people see you as being, like 'cause you look normal [laughs] [mmm] like obviously you might look normal, but you might not*

necessarily feel the same, you know and people like, I don't obviously they don't necessarily understand that you would get tired or, you know they think that you can 'cause you look normal they think that you can do everything the same as you did before [m-mmm], you know so yeah. Not everybody's going to, obviously they understand, they know, you know, understand the situation better but, some people don't which you've kind of got to explain to them, "Well ...," you know [laughs], "Just 'cause I look the same doesn't mean to say that I feel the same," you know.

In this extract Molly stressed the difference between looking normal (on the outside) and feeling normal (on the inside). She chose to call her current status “*semi-normal*”; her previous normal life transformed in a state of semi-normality. The prefix “*semi*” explains everything: she remained the same person inside, her personality did not change; however, she could not function at the same level as she used to before the illness. Maintaining normality can be difficult for patients with acute leukaemia, both because of their impaired physical status and the physical restrictions leukaemia places on them. Transformation as a process can refer to the efforts of gradually changing the loss of normality back to some level of normality, or semi-normality. In this extract there are clear references to the subthemes of the social world and the self. This highlights how the different intrinsic elements of transformation can affect one another.

Similarly, participants stressed the importance of regaining a level of control, as Robert explains below:

I just eh, came in the first course and assumed any control and all control would be with the nurses and the doctors, and that's not the case at all. You need to contribute in some regard to managing your exposure to germs etc. The, the four-bedded one, there, there's not much I can do about that, except the hospital needs to change this policy and go for single eh occupancy. But getting things like, keeping friends and relatives at arms-length during that bad period, you can control, and I did do that, but only after, only after a few, only after too many people had come to see me, then I stopped it, 'cause it was, it was eh, it wasn't doing ... it was very good of them to come, but it wasn't helping me at all.

Robert

What Robert points out in this quote is that when a patient is admitted to hospital there is limited, if any, control left to the patient. However, this initial assumption of complete powerlessness in the hospital setting begins to shift after he suffered from a serious fungal infection during his first hospitalisation. Being concentrated on preventing future infections Robert admits that patients need to make their own efforts to improve physically. Admittedly, this is a limited level of control; however, for him it made a big difference.

When patients with leukaemia are admitted to hospital, they have to face the hospital environment and the sense of complete powerlessness. In time, they realise there are things that they can still control. Fostering independence is very important as this is paramount in their understanding and coping process.

5.5.8 Assimilating leukaemia

The assimilation of leukaemia starts within the transformation process and slides over towards growth. In this subordinate theme there were two major elements; namely, the realisation of mortality, and the initiation of reprioritising personal values.

Participants in the study spoke of the awareness of their own mortality. For example, when Andy was informed of his diagnosis by the haematologist, he was quite upset by the fact that leukaemia could be instantly fatal:

*Dr [name] said that the type of leukaemia that I have, there was a really, quite a high risk of a, a serious bleed hence the, the bruising [m-mmm], that, that could have been really quite fatal. He said he, you know potentially, potentially I could have died [m-mmm], so that, that's what, that was actually quite unnerving. In fact, very unnerving [laughs] [...] well you, you're, you're actually more aware of your own mortality ... You are actually more aware of death ... living ... [mmm], so ... and so yes, but the [laughs] ... the ... the death part, I don't wonder a lot, I don't think about that much. **Andy***

During his second interview Andy explained that in fact his experience of leukaemia made him realise that he is mortal, that his life might end abruptly. Leukaemia, like any life-threatening illness, shakes one common human belief: the one of immortality and invincibility. People are raised believing that youth is paired with strength and health and that this equation will remain till old age. Andy had already been diagnosed with a serious illness prior to his leukaemia (MS), so one would assume that he would have already realised his mortality. However, this was not the case; the transformation of his pre-existing beliefs was not easily accomplished. He pointed out that he did not overthink the fact that he was mortal; thus there are signs of assimilating the new illness but not to a full extent yet. Interestingly, when describing how he felt – he repeats twice how “*unnerving*” his experience was – and choosing not to think about death he chuckles with laughter, a sign of minimising tension. There is a sense of not feeling at ease when he mentioned the word ‘death’: he immediately adds “*living*”.

Similar to Andy, Stephen came to see how fragile humans are:

*Yeah well like that, it's definitely made me feel like you've got to just ... like, your life could sort oh just end at any time - like that. I mean if I hadn't ... if I hadn't been found, I mean I could be dead by now really, em which, that's basically what the doctor said at first, it was lucky like I got found when I did, or it could have been a lot more serious, em so it definitely made you, like that, you have that sort of feeling at times, like it won't happen to you, and all that, em but it makes you realise that it can happen to you and it's made me sort oh think, like and, life could be too short, there's no point not doing stuff if you think, if you want to. If you want to do something just go on and do it, 'cause you never know what the future holds for you. **Stephen***

For Stephen, a young and healthy adult, feeling invincible and untouchable was natural before his diagnosis. Leukaemia, however, had shaken his beliefs. He started to realise that life can end at any time. Interestingly, he repeats twice that “*he had been found*” indicating a sense of being lost, stressing that his life would have been lost. This may be an indication of finding his new true self. Here in this extract one sees how the transformation occurs and the assimilation of leukaemia is just starting to happen.

The transformation of assimilating leukaemia refers to the point when a person becomes aware of his/her mortal nature and this can be a very important element in creating an understanding of leukaemia.

This section has presented the various subthemes in the constantly changing process of transformation. Some of these elements were demonstrated more apparently and others were more subtle due to the very nature of this process. The process of transformation seems to be necessary for the process of growth to follow.

5.6 Growth

Growth, the third process, was manifested to a less extent compared with the previous two processes. This is not surprising, taking into account the point in time when participants were interviewed; they all had recently received their diagnoses (or diagnoses of relapse) of acute

leukaemia. Regardless of the time relevance, the signs of growth were still evident. Growth included seven subordinate themes: a holiday in prison, coping with leukaemia, embodiment of leukaemia, the social world, the self, counting losses and assimilating leukaemia. These elements are presented in the sections below.

5.6.1 A holiday in prison

Within this subordinate theme, the process of growth was evident when patients described their relationship with the healthcare professionals. In particular, it was the trust in the healthcare professionals that proved to be an important aspect of their growth process.

Emma, below, underscores how important she felt in this trusting relationship with her clinician:

***Emma:** Dr [name], that man is like a magic man I tell you, because straight we had an agreement straight away that, whatever happens – I want the truth, don't, don't give me rubbish just hit me straight with the truth and we've always been like that, and he has always kept me "positive", do you know and if he found you "down", if, if he used to come on his rounds, if he found me down em he'd go finish his rounds and then he'd come back on his own and he'd just sit and talk to you, which is really such a nice thing to do.*

***Constantina:** What did it mean for you to have someone, a doctor like that?*

***Emma:** Everything ... I would trust that man, no matter what, and I think that's ... I think you've got to have a trust between you and your Consultant ...*

For Emma the relationship with her haematologist was of utmost significance. She requested to be "hit" with the truth, indicating a sense of self-awareness that the news might not always be in her favour. She referred to him as a "magic man", not only because he managed to treat her AML twice, but also because of the trust he inspired in her. What made him 'magic' was the fact that he made her feel important and valued as a person and being seen as another 'patient with acute leukaemia'. In a way the Consultant gave her back her identity. Perhaps this is the reason why she did not feel her confinement as being a burden.

For the participants in the study, trust was built in two components: the amount of time spent with the patient, and the honest information they were provided with. There is a dynamic relationship between patients and clinicians. Feeling important and equal within this

relationship almost relieves a burden in their cancer journey. The significance of this relationship implies that it potentially plays a significant part in patients' making-sense process.

Kevin shared a similar experience to Emma:

Kevin: *And they do they, they do, they tell you, they keep you well updated, they're in here every day kind of thing so that, they make sure you know everything's going on and eh ... naw, I'm happy enough wi', wi' what they tell me so ... I trust them all [laughs], I think they're aw good ... yeah.*

Constantina: *Is it important for you then to trust them, to have this trust?*

Kevin: *Mmm, yeah.*

Constantina: *To feel that you're in the right hands...*

Kevin: *Definitely [mmm]. I know, I don't know how everybody feels but I definitely feel that em ... eh a hundred per cent trust, for the doctors I've been dealing with anyway [mmm], eh and I think just their attitude, they don't eh rush you or try to get away quickly or, nothing's a hassle, if you know what I mean ... you feel like nothing's a hassle and they'll, they'll kind oh do anything for you [...] It make, it makes you feel eh ... more ... relaxed about I would say, yeah so, so, yeah ... I trust them. They are good.*

Again, Kevin felt important within his relationship with his consultant and hospital staff. "Nothing is a hassle": Kevin sums up how he feels. A sense of ease and security stemming from the staff's attitude. This is what makes his trust blind, gives him permission to completely surrender to their hands, and in a way, makes his imprisonment tolerable.

The process of growth involves patients' development within this relationship with healthcare professionals. Thus, their hospital stay, starting from the decaying sense of imprisonment, can gradually transform and come to be perceived eventually being almost like a 'holiday'.

5.6.2 Coping with leukaemia

Patients' coping showed signs of growth as well, when they used more active and positive strategies. Participants mentioned that remaining positive and hopeful was crucial in their dealing with acute leukaemia. Of interest is the stoical attitude some participants adopted towards their experience of cancer.

Robert, in the following quote, explains his coping style as “*reacting*” and “*responding*”:

*A lot of it I'm reacting to or is being done by clinicians. Em beyond that coping means, again I'm responding to the problems, I have no influence over the progress but I can react to in a positive way, I think it's the best thing I can say ... it's managing me but I can respond to that positive management and as I say they've (clinicians) been very good, particularly this time around, much more. [...] it's out of my hands to a large extent so I haven't had any "What would happen if?" what would happen if... it's going to happen anyway, there's not much I can do about it, but no that's not worried me, that's not bothered me. **Robert***

For Robert, his way of coping with leukaemia is reacting and responding positively to clinicians. These are signs of positive coping: he *re-acts*. He retains the power to do things for himself. Although, for a moment there is a glimpse of decay (“*no influence*”), but he resumes power by staying positive. His stoic acceptance is of particular interest. The things he cannot have any control over, he simply embraces with stoicism. There is an interplay between his sense of empowerment and his stoicism.

Patients’ coping can grow to more positive strategies that potentially help their understanding and eventually accommodate the illness in their lives. George concluded that leukaemia was just a “*nasty*” illness that happened to him:

*It's just something that's happened to me, em [laughs] I, I, I really can't ... I, I, I really can't eh think, it's just one of those things, em, it's just happened and I have to deal with it [mmm] It doesn't, it doesn't particularly frighten me, em, I know what the consequences can be, but, you know I have faith, I have faith in eh the doctors that what they're doing is the right thing. Eh and, and things seem to be looking good, you know things, the chemo seems to be working and, that's it, it's just ... [sighs] ... it's just a, I, I don't know, you know people catch all sorts of diseases, I've just caught a, a particularly nasty one. **George***

George seems to have accepted his leukaemia, although he hesitated on several occasions and could not find the right words to describe his thoughts and emotions. Growth here is pronounced: he was not afraid anymore, he had knowledge, and he trusted his clinicians. He repeated that he “*had faith*” in them twice, indicating an unconditional surrendering. George stoically accepted what was to come.

During the interviews, participants’ coping mechanisms showed signs of growth, even during this early stage of their cancer journey. For some it meant remaining positive and hopeful, and for others embracing the new reality of acute leukaemia with stoicism.

5.6.3 Embodiment of leukaemia

Patients with acute leukaemia learned a lot of unknown terminology during their hospitalisation. Growth within this theme of embodiment relates to their becoming 'experts' by apprehending a new language.

As already mentioned in the transformation process (section 5.4.4), an exemplar of a patient becoming an expert was Ian:

When I had infections I was feeling quite rough but when, I'm not sure if that, if that classes, if that's classed as part of the treatment or not. And I know with things like central lines there's arguments as to whether infections are an inevitable part of the treatment or whether they're something that should be, which should be avoided, so ... I know that, aside from infections my treatment's mostly been fairly ... [long pause] there hasn't been that much discomfort associated, at least apart from having the central line put in. Ian

Despite his higher education, Ian had no knowledge of medical terminology. However, it is striking in this extract that he sounded like an expert. He had a working understanding related to how central lines can cause infections and in a way he even questioned the consistency of the information he had received up to that moment. He became an expert of his own body; he could identify symptoms that came from his acute leukaemia and side effects resulting from treatment procedures. With the authority of the expert, at this point, he openly came to question aspects of his care showing signs of disbelief.

This 'expertise' seems to remain even after patients' discharge, when their treatment is terminated. George described how he knew that something was wrong in his body when he finally got the news that his AML had relapsed:

About 2 months ago I'd had a, a, a cold and I knew because my immune system was still quite delicate that it was going to take, you know a lot longer than a couple of days to, to get better, but it went on for a good couple of weeks, em and I got treatment for it, you know from my local GP and it sort of cleared it up, but it didn't quite go away and then I was starting to get sort of boils coming up on my face and I was like this is sort of symptomatic of what happened the last time. Em, so I was up at the clinic, which I go eh once a month, you know the Day Clinic and they'd been taking my bloods, and I says you know I'm, I'm a bit wary here and they're going but your bloods are fine, you know there's, eh, your counts are low em, but there's, there's no, there's no leukaemia, there's no mutant cells, you're fine ... it's just it seems to be that you're marrow's not producing a lot, and I was like, "OK". So the next time I went up they went well, can we take a, a

bone marrow sample because your, your blood levels have dropped again, em, so they took the bone marrow and eh a couple of days later I got the news that the leukaemia was back in the marrow. George

George knew that something was not quite “OK” in his body. He learnt all the related terminology (immune system, bone marrow) and he recognised that what he was feeling was quite similar to what he had previously experienced with leukaemia. There is a sense of confidence in his words, because he could see the signs of a previously invisible illness. Patients’ understanding of acute leukaemia and its symptoms can undergo a process of growth. This knowledge of how their body reacts with leukaemia comes from their previous experience is finally putting a face to the illness. This is how they can identify leukaemia in case it relapses.

The element of embodiment in the process of growth takes up the form of knowledge from personal experience and knowledge from interacting with healthcare professionals. Patients recognise their symptoms as leukaemia is no longer invisible to them.

5.6.4 The social world

Within this subordinate theme the process of growth was illustrated particularly well when patients described how their interpersonal relationships had changed in a positive way. Participants in the study also spoke of the support their environment provided to them. This supporting environment helped them cope with their leukaemia.

Mary provided her experience on how family relationships grew stronger after she had been diagnosed with acute leukaemia:

I think this time, I think that we've done better at kind of not, not fighting with each other and not sort of picking and, and that we've kind of done it together em and I think that, it's been easier to sort of welcome Roy into that and sort of do it as like a family unit and be OK as a family unit which is quite nice, 'cause the, yeah at the beginning of last time my parents kind of ... they were kind of upset and you know it was like they were sort of there and they kind of nit-picked at each other, [...] so yeah I think it's been nicer this time and we've been very sort of unified this time and not, we haven't really fallen out which we kind of did at the beginning of last time 'cause it was such a sort of alien situation which it doesn't feel like this time but in the end I think that I'm closer with my sister than if it hadn't have happened, if we hadn't have, if I hadn't have been ill

*I don't think we would have been as good friends as we are, so yeah I think as a family unit we in the end [...] we were closer and are more appreciative of each other, em sort of, 'cause we saw how fragile life could be so em we were, we've been very good at remembering that, which is quite nice, we didn't do it for like just like a year and then we went back to normal, which is quite nice, so I think that's the biggest thing that I notice is that as a family we've got, we got really close, which has been nice as me and [sister] moved out and went to University that we were you know, we kept our closeness [mmm] which is nice. **Mary***

Leukaemia had strengthened the bonds in Mary's family. She came to know her parents and she came closer to them. She stressed how they became a "unit" that would deal with leukaemia as one big whole and not as individual members, thus giving her a sense of comfort and security. From her repetition of the word (three times) she makes it clear that a bonded family was one of the most important aspects of her affected social world. She describes her previous experience with the illness to have created an "alien situation", again underscoring the significance that a unified family played in her making sense of her acute leukaemia. Yet, this bonding did not come easy; it did help in welcoming the 'new' member of the family, her husband Roy. She recognised that when her leukaemia relapsed she became particularly close to her sister, whom she did not really know. Leukaemia was the reason for keeping them apart when they were teenagers and it is leukaemia that brought them together again now in adulthood.

The experience of a life-threatening illness can occasionally have a positive effect on people's lives. The process of growth here shows how the construct of family turns from comprising separate parts to a united, grand whole. This supporting environment can offer patients the necessary space they need in order to understand their leukaemia.

5.6.5 The self

Within the subordinate theme of the self, there were also signs of growth. A new, better version of the old self evolved, one that is more spontaneous and full of pride for facing acute leukaemia.

George became more spontaneous, he wanted to seize every moment of life:

Certainly when I came out eh last year after I went into remission, it did. I wouldn't say totally changed my outlook on life but it changing my outlook in a major way [mmm],

*definitely [mmm]. Em I think I was saying that, you know I was always frightened about the future and will I have enough money in a pension and will I have a roof over my head, now it's like "pffft!", I live day to day [...] You know I did quite a lot in the year I was out, that I probably would never have done before, you know. Eh, I'd book, I booked to go and see a, a, a pop band down in Edinburgh or Glasgow and I'd just go, "Well, get a hotel, get a ticket, get a train ticket ...," whereas before it's like, "Can I find somebody to give me a cheap lift down?" and it was just like, "Nut ... just do it!" you know ... so yes, in that way my attitude changed, I just wanted to take everything, you know tomorrow, I'll deal with tomorrow – tomorrow, today's today, and that's basically what I've been doing for the last year. **George***

George's personality evolved from depressive to spontaneous. His priorities had changed because of leukaemia. This new and better version of self decided to live on a day-to-day basis. In this extract George feels elevated when describing his new sense of spontaneous self. There is almost a sense of pride and accomplishment rooting in his conscious choice to live a fuller life.

Self-growth is fundamental in patients' processes of making sense of their illness and ascribing new meanings to their experience. It is not unreasonable therefore, that this theme is associated with the subordinate theme, 'assimilating leukaemia' (section 5.6.7).

Emma's self-growth was found abundantly in her account:

*Yeah I am. Yeah I am [proud], 'cause I've done it again. I've fought and I've done it again, so you can't, you can't do any better than that in your life can you? You've fought leukaemia twice and you've won, 'cause I'm, I'm in remission now ... **Emma***

Emma was very proud of herself. She managed to get through a number of difficulties in her life, first when she went to court to gain custody of her grandchildren, and now with the diagnosis of acute leukaemia. She had fought leukaemia and she came out alive, stronger in a sense; she is a better version of her previous self. There is a sense of satisfaction with how she managed to deal with leukaemia. By questioning whether a person can accomplish anything better than gaining the gift of life twice, basically she wanted re-approval of her achievement.

When the self is in the process of growth there are signs of the ultimate goal of having made sense of acute leukaemia. In this study, participants described the characteristics of this new, grown, better self.

5.6.6 Counting losses

Being able to maintain the normality and control over patients' lives involved a process of growth. Some patients managed to maintain their normality, as they were allowed by the nature of their treatment plan. For instance, Stephen, after his first month of hospitalisation, received the rest of his chemotherapy as an out-patient. In the following extract he described how he managed to maintain normality in his new life that included hospital visits:

*I'm feeling OK and the treatment's going well and I'm kinda adapting tae it, I'm feeling quite positive about it now. Like I've, I've even been able to start going to the gym and that again [mmm] and getting back into just like a daily routine that I had before, so it's a lot easier that way [...] Well that's definitely, that's what's helped get me through it, I think, the fact that I can actually have a normal life still rather than at first thinking, "I'm going to have 6 months of being so depressed, not being able to do anything," em but to think only, basically just a month after I got diagnosed to be out, feeling fine, you know to go the gym and stuff em, yeah, it makes a big difference [mmm] in dealing wi it [...] Like I think they think that I'm doing it because I want to be where I was before [mmm], like when I'm training and that, which is true, but I think they think that I'm not up to it but I want to be there, but I'm prepared to just try and get there even though I'm not ready to be there which isn't true, I'm only doing it because I feel like I am ready [mmm], to do it [mmm], and just because I've got cancer I don't see why I should not be able to do, I mean if I'm feeling up for it then, "Why not?" I say. **Stephen***

He managed to get back to his normal routine by going back to the gym. He also stresses the importance of having a normal life. Stephen is "*feeling up for it*". And he clearly admitted that he wanted to go back to his status quo before the illness ("*I want to be where I was before*"). Thus, he smoothly moves to his previous normal life of exercise. Clearly, this extract has references of coping strategies in the process of growth (positivity, hopefulness). Hence, maintaining a normal routine seems to help patients' adaptation.

Maintaining a normal life was elementary in the process of growth. In order to retain this level of normality, patients' social environments seem to play an important role. Kevin explained this in the following quote:

I think everybody together has just tried to be as normal as possible [mmm], so any kind o' change would knock that normality if you know what I mean, so the only way to really deal with it and really get on wi' things is just to keep it as it was before, so that's just what we've done, we've just got on with it, so it's not really changed anything. Em, although I don't have to do the cat litter ... I, that used to be my job and I don't have to

do that anymore for infections so, that's changed [laughs], but apart from that nothing no, it's not changed at all, they just carried on as they were. Because like I said it would not, it would, it wouldn't be normal if it, if it was different. It wouldn't be the way how we, we were used to it so, it's all just the same, which I'm glad for, it's good. Kevin

For Kevin, losing normality was a major threat. The members of his social environment reinforced and sustained a level of normality for him, by not changing their behaviour towards him. He was the old, usual Kevin everyone knew, not Kevin with acute leukaemia. Kevin achieved the level of previous normality, “*it's all just the same*” he repeated with a sense of satisfaction and relief and this is suggestive of the process of growth.

The process of growth in the subtheme of loss involved participants taking actions to manage their losses. This theme was very much related to other subthemes, such as coping and the social world, suggesting the existence of more underlying connections within the process of growth.

5.6.7 Assimilating leukaemia

The accommodation of leukaemia in a person's life story is the final result and goal of the process of making sense. Participants in the study, and particularly the ones whose leukaemia had relapsed, felt they were offered a second chance. All participants emphasised that leukaemia, like other types of cancer, has made them see their life from a different perspective.

Emma insisted how her life priorities had changed after leukaemia:

Emma: ... but I'll tell you what the leukaemia does do, it changes your attitude to life. Things that ... you worried about previously, do you know what I don't give a damn about those things anymore. I don't let anything worry me, apart from coming to the clinic, about my blood count but, nut I don't. I don't care. Life's too short now. Do you know when you get aw these, the really petty things that you used to worry yourself and no doubt you do it as well, you worry about silly petty things. Do you know, it's a waste of energy. I, naw it, I don't care anymore, I don't care. It really changed a lot of my thoughts when you get a brush wi death, it does ... it makes you realise what's really important and what isn't.

Constantina: What is really important for you now?

Emma: Surviving ... my kids ... it really, everything else can just go to the pot, I don't care. I really don't care. I used, I did use do like worry myself and, now I go to sleep every night with my head clear, I don't care, whereas before you'd go to your bed and your head's cluttered ... no, no mine ...

Emma went through a re-prioritising process. She decided what was important in her life and what did not matter anymore. She used a vivid metaphor to highlight the impact leukaemia had in her life: she was “*brushed with death*”. This was the first time during the first interview when she actually used the word ‘death’, by recognising the fatality of leukaemia. She emphasises her new priorities by using the phrase “*I don't care*” four times. Staying alive and being with her loved ones are her top priorities. It is an inherent part of human nature to focus on trivial matters. And a life-threatening situation does exactly this to the person: shifts their locus of attention to what is genuinely important, being alive and surrounded by people who are significant in their lives.

Another example was Mary and her family. As a unit they learnt to appreciate life more after her leukaemia diagnosis:

*And I think we all sort of began to appreciate little things more em which is quite a nice trait to have, it helped us to appreciate each other which is nice [...] Well just you know like we'd get, we'd get up and we'd go for a walk and we would just appreciate the life that was ... it sounds really cheesy, but you know you just appreciate what was around you or would appreciate more what, what we had em, you know like our lovely home and em that we had, you know both parents and that they were with us and that they loved each other and they loved us and em, yeah we began to see just little things and began to become more appreciative of it, so yeah just ... which is a nice, what I began to see that we, and that we would point things out to each other and be like ... “Oh, yeah, I'm grateful for ... such and such,” and we kind, kind of carried that on and it's been quite nice to sort of, I don't know, appreciate things more you know, be grateful for the things that we have more. **Mary***

Remembering leukaemia during remission seemed to help Mary and her family appreciate what was earned from it. She describes the essence of enjoying the little things in life; being surrounded by loved ones and actually verbalising their emotions to one another. This was what leukaemia taught them: to be a family unit. She explained that they “*appreciated life that was*”: they took time to feel grateful for the gift of being alive. Mary almost felt embarrassed through her fear to sound “*cheesy*” but at the same time she went on to justify her emotions.

Facing a cancer like leukaemia can shake a person's core belief system that can then initiate an appraising of personal values and beliefs. This may even result in adapting core global meanings that will not fit in the newly formed belief system.

The process of growth, similar to the processes of decay and transformation, involved a variety of elements, which are possibly even further linked to one another. This process was the least apparent compared to the other two, indicating that perhaps time (among other factors, such as personal characteristics, gender, and culture) is important to allow the process of growth to take over. However, the findings of this study suggest that even in the early stages of acute leukaemia there is the possibility for patients to make sense of acute leukaemia and show signs of its assimilation in their lives.

5.7 Chapter summary

This chapter presented the first part of this study's findings deriving from the patient dataset. The three processes identified – decay, transformation and growth – seem to co-occur in patients that are close to their diagnosis of acute leukaemia. However, the magnitude of each of these processes, that is to say the strength and length of duration of the processes, remains unclear. For the participants in this study, and because they were near to their diagnosis, the decay process seemed to be more prevalent than the other two, while growth was the least expressed. Even so, participants did show elements of all three processes, thus supporting the idea that even at the initial stages of the cancer journey there are elements that transform and grow as well as decay.

CHAPTER 6 – Findings: Carers’ making-sense processes

6.1. Introduction

In this chapter, findings from the family caregivers’ dataset are presented and supported by quotes from the participants. Because of IPA’s idiographic nature, data collected from the caregiver group were treated as distinctive and not linked to the patient dataset. The researcher gave adequate space and time between and during the analyses of the two datasets to ensure that new themes would emerge from the analysis of each group and that they would not infiltrate across datasets. However, it is acknowledged that as the researcher had a set timeframe for this PhD thesis, the possibility of similarities among the themes remains.

Data analysis followed the IPA guidelines as these were described in Chapter 3. Family carers make sense of acute leukaemia through three processes, namely: entering, navigating, and transcending limbo. A number of subordinate themes were identified in each of these processes which are analytically discussed in the following sections.

6.2. Participants

Family carers were invited to participate in the study after being identified by patients. From a total of thirteen patients approached, twelve caregivers were nominated (one patient did not want to involve a carer in the study) and invited to participate in the study. Three caregivers declined to participate for personal reasons and one failed to follow up on their invitation due to their busy schedule, resulting in the final sample of eight family carers.

The participating eight family carers shared their experiences of having a member of the family being diagnosed with acute leukaemia. Contextual information to introduce each participant is provided below. As seen in *Table 6.1* below, the majority of the carers were patients’ mothers and had high educational level. This is further discussed in Chapter 7.

Table 6.1. Demographic characteristics of family carers

Characteristic	<i>n</i>
Age	
25-34	1
35-44	0
45-54	3
55-64	2
65+	2
Education	
Primary School	2
High school	1
College/University	5
Relationship type	
Spouse	3
Mother	5
Place of interviews (n=16)	
Hospital site	8
Home	3
Other (i.e. work place, Maggie's centre)	5

June

Ian's mother was in her mid-50s at the time of his diagnosis. A mother of two, she was divorced several years ago and lived with her partner in Southern England. She was a community caring professional and worked part-time. She had to commute by train every two weeks to spend time with her son. She chose the first interview to be conducted at the local Maggie's centre. During the course of the study, Ian was transferred to the South of England to complete a part of his treatment. The second interview was conducted via phone in a quiet room at the University, as June still wanted to participate in the study.

Jennifer

Andy's spouse was in her late 50s when the interviews were conducted. She was working as full-time nurse, reaching retirement, at a rural hospital. She had been married to Andy for nearly four decades and had survived gynaecological cancer several years ago, after the birth of her son. Both interviews were conducted in her office at her workplace. She was also

completing a psychotherapy course in the South of England and planned to open her own practice after she retired from nursing.

Kirsty

Stephen's mother was in her late 40s. Kirsty was also trained as a nurse but left her nursing career to work in the family business after she got married. She had another son. Both of the interviews were conducted in the back room of her family business; a shop.

Jane

Jane was in her late 40s when one of her four children was diagnosed with a rare type of acute lymphoblastic leukaemia. At the time she was working part-time. Both interviews were conducted in the hospital, in a quiet room, just before she went to visit her son. Her son was 23 when diagnosed and was also invited to participate in the study; he declined as he thought *"it wasn't his thing"*.

Linda

Robert's wife was in her mid-60s at the time of her participation in the study. They were married for more than four decades and had three children, one of whom had epilepsy and died several years ago while they were on a holiday trip outside of the country. Both interviews were conducted at the hospital after she visited Robert.

Marion

Marion was a 70-year-old woman, the mother of George, whose husband died of AML some years ago. Her husband was working in the Navy and was away from home for long periods of time; therefore, she raised her three children almost by herself. Like his father, George was diagnosed with AML and at the time of the interviews his AML had relapsed. Both interviews were conducted at the hospital.

Pam

Kevin's illness found Pam in her late 40s. She had another son, a few years younger than Kevin, and a teenage daughter. Her husband worked offshore. She was working on a part-time basis. Both interviews were conducted at her home.

Roy

Mary's husband was in his mid-20s when her lymphoblastic leukaemia relapsed. They have been together for 18 months, and married for three months. Roy was working offshore as an engineer, but decided to give up his job to be with his wife. Since she relapsed, the couple moved into her parents' home. He kept in touch with his parents mainly via Skype. Both interviews were conducted at the hospital.

6.3. The maze: entering, navigating and transcending limbo

Acute leukaemia, for family carers, was like living in a state of limbo. Etymologically, the word limbo derives from the Latin 'limbus,' meaning 'an ornamental border to a fringe' [411]. Limbo in Roman Catholic theology is a place located at the border of Hell, where the innocent souls of unbaptised infants remain because they cannot enter Heaven [411]. In its modern usage, the term 'limbo' is used to describe a transitional state or an intermediate place that is characterised by uncertainty, powerlessness and a sense of unknown threat. Family carers' sense-making processes pertain to this attribute of limbo.

The analysis of the data revealed three main processes with which family carers created their meanings of acute leukaemia: entering limbo, navigating limbo, and transcending limbo. Once their loved one received the news of diagnosis, they entered in a limbo state, dominated by uncertainty about the future. Within this process their efforts to conceptualise leukaemia were identified as was the range of impact on their lives.

In the second process, carers had to navigate limbo. This involved several aspects of steering through their social world and their ways of dealing with the hospital environment. In terms of steering through their social world, carers had to manage their social world by involving the

wider family circle, colleagues, and other acquaintances, as well as with the support they were or were not receiving. When steering through the hospital environment they valued the trust and security inspired by the clinical team. They described their diverse information needs, which, along with the sense of security the healthcare professionals instilled in them, enabled them to ‘surrender’ their loved ones to experts’ hands.

Finally, the last process identified was the transcending of limbo. This process was dominated by the various coping strategies they employed, their acting as facilitators and their efforts to reconcile the illness in their lives. Family caregivers utilised numerous coping strategies to adjust to the new reality of acute leukaemia, such as focussing on delivering tasks, stoicism and comparing/contrasting with previous stressful events in their lives. A core element of transcending limbo, closely linked to coping strategies, was carers acting as facilitators for patients. Their efforts were focussed on managing their multiple roles, and also on masking their emotional responses as an ultimate protection act. They tried to find new routines that would enable them to be present at the side of the patient throughout their challenging cancer journey. Eventually, family members showed signs of reconciling leukaemia, either by reprioritising personal values, appreciating life more and strengthening family bonds.

An overall table illustrating the superordinate themes identified for family caregivers is provided below (*Table 6.2*), together with a table reporting themes across each participant (*Table 6.3*).

Table 6.2. Master table of family caregivers' findings

Superordinate themes	Subordinate themes	Emergent themes
ENTERING LIMBO	<i>Conceptualising leukaemia</i>	<ol style="list-style-type: none"> 1. Journey to diagnosis 2. Leukaemia taking away choices 3. Leukaemia invisible 4. Causal attribution
	<i>Leukaemia “rocks your world”</i>	<ol style="list-style-type: none"> 1. Leukaemia life-changing 2. Sense of unreal 3. Cascade of emotions 4. Emotional distress 5. Feeling powerless 6. Loss 7. Fear 8. Uncertainty
NAVIGATING LIMBO	<i>Steering through the social world</i>	<ol style="list-style-type: none"> 1. Supporting sources 2. Impact on social world 3. Support for the carer 4. Social circle - Leukaemia disconnecting 5. Carer: the link with the outside

Superordinate themes	Subordinate themes	Emergent themes
		world
	<i>Steering through the hospital environment</i>	1. Sense of security (in hospital) 2. Trust in clinicians (burden) 3. Information needs 4. Surrendering to the experts
TRANSCENDING LIMBO	<i>Coping</i>	1. Comparing – contrasting 2. Dual/shared coping 3. Cascade coping 4. Cognitive processing 5. Task oriented coping 6. Stoicism 7. Living on a daily basis 8. Using old frames of reference 9. Fight-or-flight mode
	<i>Facilitating</i>	1. Living on a daily basis 2. Pursuing positivity 3. Carer multitasking 4. Emotional masking 5. Maintaining normality (task) 6. Minimising uncertainty 7. Efforts to find a new routine 8. Being there for the patient
	<i>Reconciling</i>	1. Reprioritising 2. Restoring balance 3. Strengthened bonds, reconnecting 4. Life appreciation 5. Being hopeful 6. Changed life 7. Self-awareness

Table 6.3. Presence of subordinate theme in each family caregiver

	<i>June</i>	<i>Jennifer</i>	<i>Kirsty</i>	<i>Jane</i>	<i>Linda</i>	<i>Marion</i>	<i>Pam</i>	<i>Roy</i>
Conceptualising leukaemia	YES	YES	YES	YES	YES	YES	YES	YES
Leukaemia ‘rocks your world’	YES	YES	YES	YES	YES	YES	YES	YES
Steering through the social world	YES	YES	YES	YES	YES	YES	YES	YES
Steering through the hospital environment	YES	YES	YES	YES	YES	YES	YES	YES
Coping	YES	YES	YES	YES	YES	YES	YES	YES
Facilitating	YES	YES	YES	YES	YES	YES	YES	YES
Reconciling	YES	YES	YES	YES	YES	NO	YES	YES

These three superordinate themes were created in an effort to clarify the challenging and perplexing impact of acute leukaemia on family carers. In contrast to the three processes identified in patients' accounts, they seem to follow a more linear process of creating meaning of their experience. This is not to say that carers' sense-making processes are less intricate than those of the patients. To further clarify this, the state of limbo resembles a three-dimensional maze (Figure 5). Family carers only realise that they are in a state of limbo when they are notified about the diagnosis. However, the actual 'gate' in the limbo-maze is when the initial symptoms appear and the visits to the healthcare services begin. After 'entering' the maze, carers start their navigation; a process that can be long-lasting. They may reach numerous dead ends in their efforts to transcend the maze; some may never transcend it. Eventually, the method of transcending or finding an exit point to the maze may vary: there is more than one exit point.

6.4. Entering limbo

Receiving the diagnosis of acute leukaemia for a loved one was the starting point of entering the state of limbo. Affected in a similar way as patients were, carers entering this intermediate place of neither here nor there began to conceptualise the illness through describing the journey to the diagnosis, the aftershock of receiving the diagnosis (either being present with the patients or being told by patients themselves), and their causal attributions of acute leukaemia. Acute leukaemia was an illness that 'rocked their world' in many ways, spawning uncertainty, a sense of the unreal, powerlessness and fear, loss, and distress. As their sense-making process was initiated, this phase remained blurred and was perhaps the most challenging for carers. A detailed analysis of this first superordinate theme follows.

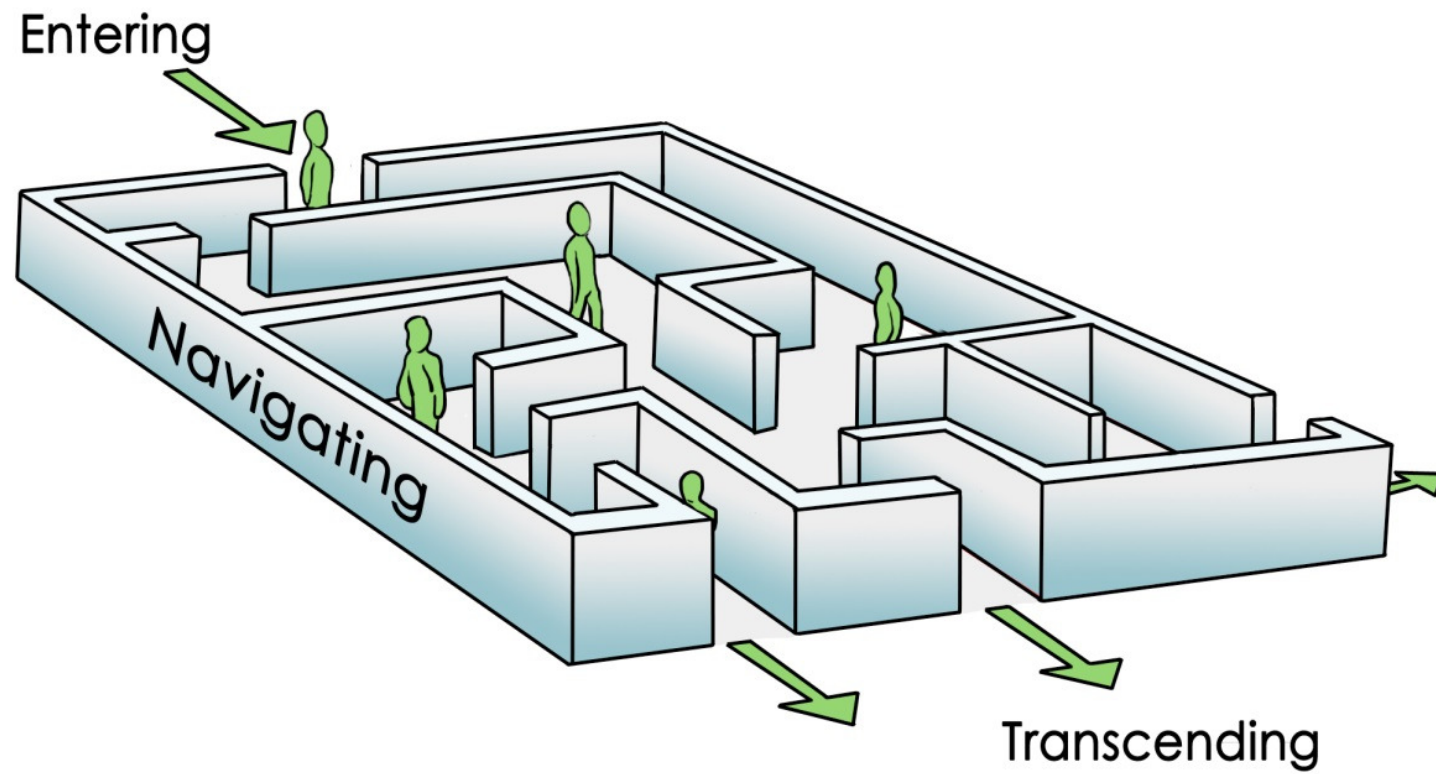


Figure 5. The maze of limbo

6.4.1 Conceptualising leukaemia

In conceptualising leukaemia, five elements were identified in the process, none of which follows a linear order. These elements were; the descriptions of the journey towards receiving the diagnosis, the feelings of shock, the mental images of leukaemia, the need to find a cause for the illness, and finally, their difficulty to conceive and understand acute leukaemia.

During the interviews family carers shared patients' visits to their GP practices. The journey to receive the diagnosis of acute leukaemia often involved barriers set by the health system to arrive at a diagnosis. For instance, Kirsty, in her account, stressed the numerous times her son had seen a GP before he finally received his diagnosis:

*Well, he had come back from his holiday with a sore throat and the next day he phoned the doctor's, got seen up at the doctor's and he was basically just told it was a viral infection and just to go home, this went on for 5 weeks and he was at the doctor's I think about 5 times in between that period and in between times they had taken blood for em glandular fever initially they wanted to re-check his bloods, em but they also said bring an overnight bag, that he would probably be staying in and, as much as I never thought for a minute it would be leukaemia I was initially thinking, "Oh my God," you know, "What are we dealing with here?" and because it was a sore throat he'd always complained of I was beginning to think you know, "Is there something, a tumour or something like ... " that was kind of my initial, I was thinking, "Oh ... " you know ... " [...] you know he was so healthy, so [laughs] well and healthy and there was no other reason to suspect that there was anything ... more sinister, as far as I was concerned. I knew he wasn't well but ... definitely never, not for a minute, until that phone call and then I suddenly thought, "Oh my God". **Kirsty***

The need to share the particularities of the journey to the diagnosis is an intrinsic part of making sense. Carers needed to start from the beginning of how they first encountered leukaemia. The multiple visits to the primary health sector are not uncommon, considering the symptomatology of acute leukaemia. This can indeed create frustration and increase distress at that early stage. Going back and forth and being told that it was only a case of a bad cold or glandular fever was what made the announcement of acute leukaemia a bigger shock. Kirsty's frustration aside, regarding the inconsistencies of the healthcare system, it is of note that the possibility of having a tumour crossed her mind after the call from the hospital. Because of her nursing training, this seemed like a reasonable explanation. She characterises leukaemia as "*sinister*" to counteract its 'innocent' signs. She further explains:

*... so once we hit the ward the nurses were saying things like, "Have you had any bleeding gums?" and Stephen had had bleeding gums but again it hadn't been something that we'd associated with him being unwell because he'd been going down to the Orthodontist and he'd been going to be getting braces [m-mmm] and they'd been saying to him to do all this flossing and things with his teeth and he'd said you know, "My gums have been bleeding a bit and ... ," I just kinda put it down to that, and then they were saying like, "Have you got any bruises?" and, as I say he had this huge big bruise that had appeared but then actually once we started looking ... there was more little bruises on his legs and things and, and on his arms that we just hadn't even, you know he hadn't picked up on and we weren't aware of and eh ... "at the worst we could be talking about leukaemia", you know that was just like ... "How can they be telling us this?" you know and em, really at that time they hadn't done any other tests, you know we're thinking, "We've just arrived here and already we're getting told that it could be leukaemia. **Kirsty***

The signs of leukaemia were gradually revealed by nurses and doctors. Minor issues, like bleeding gums, that she could initially explain, were now of more significance. Leukaemia was working inside the body presenting small manifestations that did not stand out from the ordinary. This part of the journey is very important, representing the point of realisation of the limbo: how the illness is announced. Kirsty, in this extract, was not prepared for what she was about to hear. She had her own assumptions regarding what her son could have, and certainly, the innocent signs were not indicating that kind of worry. When she received his diagnosis, she questioned clinicians' authority, and almost denied the news of leukaemia. How could they be certain of such a serious diagnosis only by reading a simple blood test? Her reactions are indicative of the emotional status she was in at that moment. Leukaemia, once explained as a 'cancer of the blood', is directly linked to death, as any type of cancer is.

The diagnosis of acute leukaemia can come as a shock, either because of the initial signs being attributed to other conditions, such as the common cold or glandular fever, or because of the complete absence of signs. Moreover, in addressing the initial worry of which illness symptoms could indicate, carers may turn to other sources of information, such as the internet.

For Pam, leukaemia was an illness that children have, and the fact that Kevin had a swollen lymph node led her to believe that he could be facing lymphoma. Again, her assumption was guided by her previous experience. She wanted to be prepared, therefore before they went to meet the haematologist she looked it up on the internet. Hence, Pam, went back to her knowledge base (lymphoma), updated her knowledge (via the web) and came up with a 'verdict'/diagnosis. This is why the diagnosis of acute leukaemia came without warning:

The only knowledge I had of leukaemia was when I worked at the children's hospital, em so because he had a swollen lymph node I felt sure that when we went to the appointment that day, if he didn't have a blood infection which was the most, the best diagnosis he could ah had, em I felt sure if we were going to get bad news it was going to be lymphoma, so when she said leukaemia, it completely shocked me. Pam

Similarly, Linda stresses the rapidity of how leukaemia changed her life; in Robert's case, leukaemia had no signs, therefore it was harder to understand and the shock was even greater; she was "bewildered":

Just an, an instant life-changing experience ... em with no symptoms it was just a, a real shock to both of us, 'cause he didn't feel at all unwell, and we were just about to go on holiday so it was a bit of a "blow" [...] But, you know difficult to adjust to, you know something as devastating as that when you, when you haven't even felt ill. That, that was the "bewilderment" as well, that, you know he hadn't felt ill. And for the first two weeks, even during the chemo he didn't feel ill, eh was walking about, he was dressed, he would walk me to the exit, he would come back, thinking, "Well, this is a, this is a breeze ... this is a walk in the park," – really, it wasn't as bad as we thought and then 36 after, hours after the chemo finished he just sort of went down to zero, so that was another shock. Linda

The invisibility of the illness makes it harder for the carers to understand, to accept and cope with the new reality. In Linda's extract, note how she uses the second person ("you haven't even felt ill") and as she goes on she changes to third person ("he hadn't felt ill"). This use of language places the carer closer to the experience and is indicative of how immersed the carer can be in the cancer journey and how challenging it can be to understand acute leukaemia. While the illness remains invisible, even during the first period of receiving the chemotherapy, when the side effects become apparent, a second shock wave is waiting. The treatment side effects then make leukaemia visible to the carer and therefore make it real.

Pam found it hard to understand Kevin's ALL because he "looks" healthy when he should not. Gaining weight is not part of the mental image of a sick person:

It's not because you forget what's going on but you just think ... you look so well you can forget how sick he is, em 'cause he's really weak just now, he gets tired really easy and ... but em ... and because he put on weight wi' the steroids he's still got some o' that so he, he doesn't look like a sick person. If you passed him in the street you wouldn't know he was ill, but I think that's a good thing, em 'cause it would be tougher to watch him looking sick, it actually makes it easier to look at him because he looks well, so you don't, apart from the, the tiredness you're not thinking, "Oh, he looks so dread-, ... " or, "He

looks poorly, he looks ... he doesn't look well," and I think that would make you worry more [mmm], but because he looks well it's, it's OK just now. Pam

In contrast to the rest of the carers, Jennifer knew from the beginning what she was dealing with:

I, I was looking at the symptoms but I also knew that one of the side-effects of the treatment that he had been for his MS I, I immediately thought of leukaemia because somehow or other it was in my head [mmm], when I, certainly when I saw the bruising, em, so and, and then more, more bruises and, and, and it just wasn't explained, he just couldn't explain the bruising, you know ... I thought to myself, well he can't possibly be falling, I never saw him falling about as much as that to 'cause bruising [mmm], em, so it, I just, I just thought – leukaemia, yeah. And I'm glad I did [laughs] [...] and that's why, you know Dr X said if he hadn't been started treatment within an, an hour that would have been it, he would have ... if I had left it, you know he would have been dead ... so, yeah. So that came as a shock really [...] [mmm], I mean it was, it was acute, so, and I tried to think exactly when it could have started [mmm], you know before that, it must have happened maybe a few days before, perhaps, I don't know, m-mmm. Jennifer

Arguably, Jennifer was not the 'usual' carer, she was a nurse, had survived cancer herself and had a certain cause for Andy's leukaemia (the medication he had received several years back to treat his MS). Nevertheless, she still experienced shock from the fact that leukaemia could have been fatal for Andy.

Of particular interest in this subtheme are the mental images the carers had of acute leukaemia, which were often portrayed in the form of suppressed memories. Irrespective of how well hidden the memory was, the diagnosis of a loved one was enough to retrieve and vividly describe it. These primary encounters may have helped, therefore, to shape their initial understandings of leukaemia at the point of diagnosis. For example, Kirsty provided an emotive image:

I can only ever remember nursing one patient with leukaemia and it was the early stages of my training and I remember her having a, a Hickman line in as we called them then and again to me I don't know but I get the feeling that was all quite new the way her treatment was and that was like 20 years ago and at that time I just remember, I can actually vividly remember this lady, just, and I don't think I had a terribly lot to do with her but I, I just seem to remember this patient with a Hickman line and just looking so ill and you know getting treatment and it was leukaemia that she had and that ... I don't know if it's something I've always, I don't think I've subconsciously ever thought about it and I don't know if it's just because of what Stephen is going through that I've brought

this memory back into my head, I don't know, but as I say that's really my only dealings with leukaemia and that was I suppose what I was thinking about Stephen, you know he's going to be in hospital ill getting treatment and losing his hair and being unwell and you know that ... all the things that you kind of think go hand in hand when you get a diagnosis like that, so ... **Kirsty**

What formed her perception and initial reaction to leukaemia was that image of a person with a central intravenous line, looking very ill, frail, receiving chemotherapy. She reasonably put her son in the place of that lady: will this soon be him?

A patient with acute leukaemia is a patient receiving cytotoxic chemotherapy. Commonly, chemotherapy is linked to hair loss, therefore alopecia was part of this core mental image of the 'patient with leukaemia'. June had a similar mental image of a seriously ill person: one with no facial hair:

He's put on weight, he's very articulate again. [...] Em, and sometimes it's hard to remember that he's ill, you know 'cause I've sort of got used to his look and I'm sure with this next course of chemo his hair will totally fall out again, em, I'm hoping his eyebrows don't go, they haven't gone yet, 'cause then you look even less healthy somehow, you know you then look like someone who has cancer much more if you don't have eyebrows, I know it's silly but... **June**

Of particular interest in the above extract is the fact that Ian's leukaemia stayed invisible in her eyes despite the fact that his hair had already fallen out. She saw the same person, her son behind the face of acute leukaemia. Carers may worry that the illness can consume and hide the true face of their loved ones. This becomes clearer in Marion's mental image of leukaemia, where she recalled her first memory of leukaemia:

The first time I heard about leukaemia was, I was just young ... and eh this eh little boy em had leukaemia [m-mmm] and, you know I said to my gran, "What's wrong with him?" "Oh, he's got leukaemia and he's not very well and I don't think he's going to be well," and I thought, "Ooooh, I've never heard oh that," that must be it, you know and I remember, she took me, he died that night and she took me the next day to, to see the little boy because we used to play together and that, and he was in a ... box, sitting on the table and it was all white, eh, like Broderie Anglaises [m-mmm], you know, and blue ribbon and ... at first I was frightened and then when I looked and I thought ... "No, that's still you there," you know, and that was it, that was the first time I'd ever seen anyone dead. **Marion**

Marion's last phrase, "*that's you still there*", even though it originates from her memory, sums up a major worry of the carers: whether acute leukaemia will change their loved ones. Also, her description further supports the initial linkage of leukaemia with death, at least at the beginning of the cancer journey.

A central part of conceptualising leukaemia when entering limbo entailed a desire to attribute a cause to acute leukaemia. Family carers had the need to find what caused their patient's leukaemia in order to be able to start making sense of it. Reasoning with leukaemia, despite clinicians' instructions that the exact cause of leukaemia is not known, seemed to provide them with some closure. For instance, June explains her thoughts:

CP: Have you ever thought why it happened?

June: I have. Em, they say there's no real reason, but when I saw the reasons one of the first ones they put is toxic poisoning ... and when Ian was about 12 I had a next door neighbour and he was just mad and he decided to move the boundary and he poisoned the whole of my garden twice and I keep thinking could that have been the reason? And I will never know, and there have been times when I've been there and I've been really upset and angry, but it, I've had to move away from that because it just takes away all your, all your energy and actually I can never prove that it was that, and we will never know, and you just feel sick, it feels like I didn't protect my children properly if that was the case.

In this extract, June needs to have a reason and to be able to explain why Ian's leukaemia is evident. The causation she found, however, apart from giving her closure, gave her more worries together with a sense of guilt. This feeling of guilt stems from her fear that there is the slightest possibility that she did not protect her infant child.

Similarly, Marion's perceptions of health and illness were not uncommon:

When it happened to George I was devastated, 'cause he was a walker, he was a climber, he was all for fresh air and that em, that really hurt me and I thought well he's just young and why does he have to have it? Marion

She could not understand how her son who was fit and young should have leukaemia. She even disclosed that at least her husband was older, older enough to cope with leukaemia better. In order to make sense of George's leukaemia she tried to find commonalities between him and her husband:

*So I sat down one night and I'm thinking to myself now what could have done that? And then I thought ... X (husband) has been offshore for quite a long time, now he came back from the Merchant Navy, he said it's time that we had more time together, you know, and I says he's been offshore and George's been working offshore, I'm wondering if it's something carcinogenic that it's happening on the rigs you know with the oil... **Marion***

Another causal attribution involved the theory of stress as a potential carcinogenic agent. Roy shared his line of thinking, where excess stress due to the type of his job and the expectations placed upon Mary for her studies caused her leukaemia to relapse.

***Roy:** I was away as well [mmm], and she was doing her studies and she wasn't having fun and it was really, really stressful and she was stressing about everything and she was worrying about me as well [mmm], 'cause eh she felt I was doing a very dangerous job [mmm], and eh she was just worrying about everything, and eh I connected with how stressed and worried she was and you know this, this all come back again [mmm], but they said that there is no, there's no connection ...*

***CP:** But in, in your mind ...*

***Roy:** ... in my mind that's how I feel [mmm]. Em so now I just, I just don't know, I just don't want to ever stress her out again, and keep her as ...*

Roy formed his own explanation. In fact, he thinks that by removing the cause (the stress he caused her) then the effect (another relapse of illness) will be avoided. Like June, he seems to blame himself for causing her stress.

To summarise, carers' efforts to conceptualise leukaemia were not always successful. The fact that leukaemia can be invisible prior to diagnosis, therefore leading to a bigger shock when announced, or even later after treatment, is one major barrier to their efforts to make sense of the experience. Another issue is the fact that leukaemia has no known cause which leads carers to shape their own explanations of why leukaemia happened.

6.4.2 'Leukaemia rocks your world'

An integral characteristic of the maze of limbo is the prevailing sense of disorientation. This disorientation is detailed in the second subordinate theme 'leukaemia rocks your world' which includes the impact of acute leukaemia in the lives of carers themselves. Leukaemia 'rocked' their life, changed everything in an instant. They went through a cascade of emotions,

including a sense of the unreal, feelings of powerlessness, loss, fear and uncertainty increasing their levels of distress. Pam summed up her emotional response when she heard her son's diagnosis:

You felt like your head was going to explode ... and your heart, and your stomach [laughs] ... the whole lot o' them together, em and I think that's about the most scared I've ever felt I think so ... it was em ... a big scary experience ... it's like a huge adrenalin rush when you first get diagnosed and everything that happens quickly and this I what they're going to do to you ... it just rocks your life really. Pam

It was as if Pam's vital organs were about to explode. And, then, the adrenalin rush put her in a 'fight-or-flight' mode, which is the typical response to a stressful stimulus. The 'fight-or-flight' response is controlled by the autonomous nervous system which mediates the production of neurotransmitters (such as epinephrine). The body, through a series of chemical changes, is 'prepared' either to stay and fight, or to run away from the stimuli (flight).

But the sense of chaos only sets in after the news of the diagnosis. June shared how her life was dominated by her son's leukaemia:

So yes, just the ordinary-ness would be really nice, yeah, yeah. 'Cause all the time there's nothing else I think about really. Em, even now when I'm going back and doing bits of work it's there 99% of the time. So I'd like the order in it, ordinary-ness, just going for walks and not thinking about it, seeing people, doing things, yeah a bit of that, not worrying, I think it's the worrying and this sort of, occasionally going out without the mobile phone and not worrying about is it going to ring, that sort of stuff would be really nice, yeah. June

Her previous worry-free life is replaced by the constant thought that her son has acute leukaemia. The previous order of things was lost. This relentless thought can have a paralysing effect, indicative of the emotional burden carers have to live with. Roy provided a 'stillness-in-motion' picture of the loss of the previous order:

It feels like eh time has stopped and everyone else's life is sort of continuing, but our lives are going really slow and each month feels like a year and em ... but not in a bad ... not in a bad way that time is dragging or something like that, eh just in a sense that there's so much happening in, in a month and so much we're thinking about, decisions we have to make or things like that and you're not looking, potentially looking forward to the next month because of the treatment, and you, you want time to go slow. Em ... and sometimes it feels strange that everyone's just sort of continuing their normal lives and

... and eh ... and you just want it to all be better [mmm], I don't know, yeah ... so ... life's on hold until she gets better. Roy

Life for Roy has stopped, time is running on a much slower pace compared to the rest of the world, this sense is exacerbated due to the big decisions they have to make in terms of Mary's treatment, which in turn makes them feel that they want it to go even slower.

Losing track of time and living with a sense of the unreal, or derealisation, dominated the lives of the participants in the study. This state of being in a dream world, a main element of being in limbo, hindered their efforts to make sense of leukaemia. June's first experiences of acute leukaemia were indicative of this emotional status:

It felt like you're in a movie that you want to jump out of all the time, yeah, there's somebody else here. It isn't really, really happening, and then, you knew it was, yeah [...] so the early days were incredibly unreal. I think I was ... I don't know whether I was coping, I was just going through the phases of it and just making it happen. [...] So the early days were awful and horrid and, yeah, just really awful, sort of, yeah, yeah. In a dream you don't want to be in, yeah. June

June seems to relive her experience in this extract ("awful", "horrid"). Her struggle was evident even from the metaphor she chose to resemble her experience, namely that of participating in a motion picture film.

Pam described a similar experience in losing the track of time:

I think that made it real maybe, you know ... so although we, we were going through all this in here and ... sometimes in my bed at night I think, "Did that happen today or was I ... is this happening to somebody else?" and, or is it really ... you get up in the morning and it's ... just for a wee minute it's not there and then before you've stepped out o' bed it's back. Pam

The time before going to sleep is the moment of stillness, when all physical activity decreases so that the body can rest; it is at this point when the mind has the chance to process all that has been experienced through the day. Pam came to question whether what she experienced was for real, due to the fact that everything was happening at such a fast pace.

The state of limbo is also governed by uncertainty about their lives and their future. Linda's words on how she described her life after Robert was diagnosed with acute leukaemia were very demonstrative of the level and impact of the uncertainty of leukaemia:

*Well I suppose it's because my life's in limbo, you know I can't plan anything, like you know should I get my hair cut next week? Will I have, you know will I be able to, will I be able to go here ... it's not that I'm leading a wild life it's just that the normal things that you have to make an appointment to do, I think, I wonder if I'll be free, will I be able to cancel that so, that just interferes with, you know life ... you just, you just can't do anything. But I think at least I can get out of here every day and go home ... and he can't, so ... [slight pause] ... it's just a challenging time. **Linda***

What is unsettling regarding uncertainty is not its impact on large-scale plans, but how it disrupts the simple, trivial activities. Linda above felt the need to explain that she was not “leading a wild life”, perhaps because she worried about the impression she would give to the researcher – and the wider social circle – that could contradict the socially constructed role of the female caregiver. It seems like the only certainty of leukaemia is living in uncertainty, as Roy pointed out:

*Nothing seems very certain [mmm], nothing to do with leukaemia seems certain at all actually, everything just feels like ... it's all just good statistics and bad statistics and eh nothing seems definite that this will work or that will work, or this will definitely happen; nothing is definite [mmm], which I have realised and that's probably the most frustrating and scary thing about leukaemia 'cause you just don't know what's going to happen... it's just up in the air isn't it, you don't know what's going to happen. **Roy***

In this extract, Roy struggled with uncertainty: he kept repeating that nothing was “certain” or “definite” regarding the illness. This repetition (six times) is indicative of a feeling of discomfort and ultimately demonstrates the level of impact that acute leukaemia had in their lives (his and his wife's). Furthermore, the uncertainty is what made it difficult for Roy to understand acute leukaemia and explain why happened. For him, everything is represented in numbers he cannot relate to; these are blunt numbers that cannot give him a definite answer. The uncertainty for family carers resembles a free-fall (“up in the air”), with no solid ground under their feet, where they do not know where they will land.

Living in uncertainty increased the levels of distress and the fear of death. The mother's instinct is well portrayed here in Pam's words:

*But I was scared for him, you know you're not scared for yourself, it's ... it's more for, and you'd rather it was you is most people feel, than him 'cause even though you still think you're quite young yourself you'd rather it was you than, than, than at his age. **Pam***

Despite the fact that Pam thought she was still young to have cancer herself, she would take her son's acute leukaemia in an instant to protect her child.

Of the most distressing feelings carers reported was the sense of powerlessness. Roy describes it well:

*Probably the worst thing about this, for me is that I can't do anything, you know eh ... maybe it's something that's sort of inbuilt that you just want to eh, come to the rescue maybe, but I can't, I mean, it's not like I can jump into her body and throw out leukaemia cells or beat them up or [laughs] ... or anything like that, you know I can't do anything, em, that's the most frustrating thing, the lack of not being able to do much. **Roy***

He saw an “inbuilt” characteristic/element in his personality (or in carers) to come to the rescue of the patient. They all wanted to help their family members somehow and, yet, they felt they could not do much. If Roy could, he would jump into Mary’s bone marrow and kill all the leukaemic cells; he is almost the impersonation of a righteous knight coming to the rescue of the ones in need.

Protection, either taking the form of a mother’s natural instinct or the form of a caring husband, is an element that uncertainty takes away. Again, this is another sign of how the illness is perceived through the level of disruption it brings to people’s lives.

June described the range of different losses she experienced with her son’s acute leukaemia: loss of certainty, loss of the previous balance in their relationship, loss of knowing, loss of routines/normality, loss of his future:

*I think it's the loss of certainty, and that sounds a bit like repeating about death but the loss of, Ian isn't ... he's a different Ian, it's the loss of our relationship that we used to have, and the loss of knowing, pretty much your kids are OK, 'cause he's not OK, that sort of comfortable nice feeling em, and the loss my way of life, I mean clearly I've given major amounts of work to be here, and the loss of, just the freedom of just being able to say, “Let's go and do this,” em ... just even thinking about the loss of just being able to plan anything 'cause you can't plan anything, so I suppose it's the loss of normal everyday boring day-to-day. Yeah. [...] It's sort of loss of him having a secure life, you know just that “normality”, your kids grown up and they have relationships and maybe they have kids, maybe they don't, em ... but they're happy and settled, em, you know they have chances to get work, it's going to be really hard for him to get work now, he can't probably get insurance, he probably can't get a mortgage ... so, yeah everything is different, it's the loss or normality, just everyday life. Yeah, and that easiness ... **June***

Apart from the emotional distress, family carers may also experience increased physical distress. Their perception that they are not the ones suffering from the illness refrains them from identifying any additional distress they may experience. From the participants in the

study, Pam had such an experience. Although she seemed to understand that her son's leukaemia should naturally affect her, in the end she had different expectations of herself. In the second interview she described how she eventually had to see her GP:

*I did end up having to go and see my GP 'cause I think everything must have kind of come to a head so I was feeling a bit down and em tearful and tired all the time and so, she did say it's, she was actually surprised she hadn't seen me before she did 'cause it's bound to be affecting you so, but I think I was just kinda carrying on and carrying on and carrying on and, and then all of a sudden em couldn't be bothered with anything, you know I was doing things because I had to do them, like doing the shopping and the cleaning, I wasn't in the mood and so but I went to see her last week so she was really good. She asked me if I wanted time off work em, but I said no that would kinda add to my stress 'cause then I would be worried about being off work so em I'm keeping on at work just now and, hopefully just em things will get a bit better, but she says it had to happen I suppose, it had to eventually affect me more than it, it, than it was, well than I thought it was [...] it's funny because you know you, he's the one that's sick, but she said but you're all going through it, you know so but it does'nae feel like that, it feels like "God," you know, "he's coping with all that, you think I would manage a bit oh tiredness," and, and a bit o' stress but it's not as easy as that really. **Pam***

Pam thought that her physical breakdown happened suddenly. By masking her emotions she tried to avoid How Kevin's illness was hard to deal with. She had physical distress in the form of fatigue and sleep disturbances. Eventually, she felt guilty that she was not able to deal with the physical and emotional weight that was placed upon her by Kevin's illness, while she was not the one diagnosed with acute leukaemia.

In summary, the diagnosis of acute leukaemia can 'rock' carer's lives in a variety of ways, resulting in emotional as well as physical distress. They experience acute leukaemia through its impact: the surreal feeling, the level of uncertainty and the fear for the life of their loved ones.

Within this initial process of entering limbo, family carers are called to identify the multiple impacts that the diagnosis of acute leukaemia has cast upon them. They seem to struggle to conceptualise the illness due to its invisibility. At the same time, they go through a range of emotional responses, such as fear, uncertainty, sense of loss and powerlessness, all of which make up the main characteristics of limbo.

6.5 Navigating in limbo

After entering limbo, family carers' making-sense process involves their navigating in limbo. Finding their way in limbo comprises their main activity at this stage; they have to manage their social world, they gather their sources of support and, more importantly, they deal with the hospitalisation of their loved ones. The two subordinate themes identified – steering through the social world and the hospital environment – are subsequently presented. Again, as with the first process presented, these subordinate themes do not develop sequentially one after the other. It should be noted that there are connections among these subordinate themes and the subordinate themes of the other two processes; underscoring the value of this middle process of navigating in limbo in making sense of acute leukaemia.

6.5.1 Steering through the social world

In the subordinate theme, 'steering through the social world', there were two main elements identified: carers' need to be supported and their experiences of connecting with their wider social circle. This theme has played a significant role in the sense-making process of the carers.

For carers to recognise the fact that they themselves needed support was not an easy task. As seen earlier, it took Pam a considerable amount of time to realise that she should seek medical attention for her physical distress. The perception that the locus of attention should remain with the patient comes naturally for carers. Consequently, carers may suppress potential emotional and physical distress, increasing their burden and eventually being unable to fulfil their roles. For some carers, being able to talk to their family and friends was adequate, while others thought of seeking more professional support in the form of counselling. However, all expressed that their priority would always be their family member.

June discussed seeking professional support in the form of counselling and peer support. In the following extract it is quite apparent that she planned to seek help after her son would have finished the first part of his treatment. She acknowledged her need but at the same time she gave priority to Ian:

I am going to look for other support and I think at some point after I've seen the counsellor I might ask, I might look to join some sort of support group or something [...] I think once I've gone through counselling, I think I probably need to break a bit more, 'cause I'm quite aware that a lot of what's got me through is just keeping going, staying

strong [yeah], building around me, supporting Ian, supporting his sister, supporting my partner sometimes, and it's very much supporting his dad who em, and his dad's mum and everybody and ... June

In the above extract, June explains her need to “break” her experience into smaller pieces. At that stage she had focussed on acute leukaemia as a whole, how it affected her social world and her son. For family carers, being able to dissect the experience of having someone in the family living with acute leukaemia into smaller and more manageable components may enable them to better make sense of it. Normally, this process may require more time to materialise. Another element is June’s role as a mother being the cornerstone of support: she supports everyone in the family: her estranged husband, her ex-mother in law, her partner, her daughter, and her son. There is a link between this subordinate theme and the subordinate theme, ‘facilitating’ (section 6.6.2). Her major concern was Ian at that stage; she would facilitate his support along with supporting the rest of her family. However, she had allocated time for professional support for herself after everyone else was settled and things would have subsided a little.

Similarly, Roy expressed the same need to focus on his wife, even though he had set his support structure in place if needed:

I've got eh some good, good close couple of friends who eh just stay in contact with me and just eh see how I'm doing and want to come down and see us but obviously I've been putting them off right now because just when Mary can have visitors em ... so everyone is just there and anything I need I, I only have to ask, so we have, we have plenty of support. Roy

It is particularly striking how he described his choice as an ‘obvious’ one (“obviously”), meaning that other options were not seriously considered. Carers, like June and Roy, feel that they have a moral obligation to place the patient as their top priority by neglecting their own needs and sometimes by putting off their own making-sense processes in favour of the needs of their loved ones.

Other carers decided that they need to be supported at the same time as the patient. Jennifer, below, shared her experience:

I sorted it out a good few years ago, that em I have to be able to look after him, I have to look after myself, and that was a different time for me because you know I was feeling guilty about it and you know what do other people think [...] I felt I have to look to my future as well, em and so because I, you know I am a carer, em and this is going to be a

long-term thing, but there are things, you don't have to be dragging yourself down, you know em, you have to make the best of it, so I need something outside, you know looking after Andy, and he knows that, em and we've adapted, you know it's other people that haven't adapted [...] some of our family [mmm], you know thinking that I was incredibly selfish going off when he'd just been diagnosed with something like that, but I spoke to Dr X and I said to him that's what I would do, em, and we knew that if anything happened I would just fly up, you know so, it was organised, it wasn't just that I was sort of leaving him, but you know a lot of our family have probably found it difficult to come to terms with what we did [mmm], you know the, the decision that we made. Jennifer

Jennifer understood the importance of being supported (mentally, emotionally and physically) and the impact this could have on both herself and her husband, Andy. She explained how “different” and difficult it was for her to make such a decision. Shifting her focus on herself and her needs by creating some personal space increased her feelings of guilt. Her social circle further sustained her guilt. The perceptions of her wider family regarding what was ‘acceptable’ comprised an additional source of stress. She had gone through a reprioritising process long ago when her husband was diagnosed with another chronic illness. Another reason for her initiative to run such an independent life may be the fact that she herself was a cancer survivor. However, her need to justify her choice remained as she still wanted some approval from her social world for the choices she had made during the first phase of the diagnosis of acute leukaemia.

Carers’ social worlds play a significant role in their meaning-making processes, either by providing them support (positive influence) or by adding to their stress (negative influence). In Jennifer’s case, her family’s expectations of caring filled her with guilt, which is an example of negative influence. The social environment can affect a carer who is trying to deal with a loved one’s leukaemia in different ways. Pam, for instance, disapproved of the way her social world often reacted to her son’s leukaemia:

Some people will say, “Oh, leukaemia ... oh yeah, oh that’s fine, they can treat that,” you know and, and you’re like “fffff ... ,” and I don’t mean they don’t realise how sick he is but a lot o’ people have, have and I think they’re maybe just trying to be positive in front of you, and I sometimes find myself thinking, “God, you’ve got no idea [laughs] how sick he is,” but I don’t want to say that to people either, but I think, I don’t know if that’s like the angry bit that kinda comes in when folk say, “Oh but that’s ... och they can treat that ... ,” and, “Och he’ll be fine,” so I find that sometimes a bit, a bit frustrating, not because I want to say to people ... well maybe I do actually ... maybe I’d like to say [laughs] ... “Do you know he’s really sick?” [laughs] ... you know, em, but they’re not doing anything

wrong, I think they're just trying to be positive, em and if you're not in the situation I suppose it's maybe tougher... Pam

Pam thought people did not understand the severity of her son's condition and did not sympathise with her. In the above quotation, there is also some cognitive processing, where she tried to understand how people think, and how positivity can help. She reckoned that other people were not in her shoes and tried to justify their reactions. She wanted to be in a world where others would sympathise with her and would give her 'permission' to show how hard her son's leukaemia was for her to grasp and deal with.

June shared a different aspect of the possible negative influence in her relationship with her partner:

I've got a partner, sometimes that's very supportive, sometimes it's bloody awful because we miss each other and I guess it will test our relationship greatly. He has em had a very different upbringing and his parents were never there for him. His father was sort of, quite a bully person and he has 4 kids and if they don't ring each other for 6 months, but it's just the way they are, whereas I would always be ringing my kids, just a couple of times a week you know. Em, so sometimes our ways of doing things are very different. Em, he doesn't all, he wants to make things OK and he doesn't sort of understand that he can't, some things you can't make OK and I think he was, although he wouldn't say it, I think there's a, a tension as well because clearly I'm hardly at home at the moment and then when I come home if Ian is upset I drop everything to be there and listen to him, so it has put lots of pressure on us, but I sort of feel we'll make it through and if we don't it's not meant to be because you, yeah ... so I've got to that point. And he used to come up a lot more, but it was sort of, it was lovely having him here and I enjoyed it but then I'd be like thinking, "Actually it's getting to time to and see Ian," and there was this sort of pull all the time, so it works better if I'm here on my own. June

In June's description her partner is both a source of support and a source of worry, indicative of the double impact the social environment can have on carers. Friction in the couple had just started to make its presence as she had clearly set out her priorities at the time: her son. She acknowledged how this prioritisation may affect, even threaten, their relationship especially as they had very different experiences within their families. Particularly for close-knit families focussing on the ill family member is not something uncommon. In a world where a son has a life-threatening illness such as acute leukaemia, she determined that a mother would drop everything in order to try to help her child in any possible way she could. However, breaking her supportive links with her partner or other supportive sources can have repercussions later on.

Because of acute leukaemia's restrictions, carers often found themselves to be the link between the patient and the outside world. This, especially during the early days of diagnosis, can be perceived as a burden due to a carer's vulnerable state. For example, Jane shared her experience in the extract below:

*Well it was lovely to have the support, it's great, em some, to, to start with I didn't want to speak to anybody and my, my mum was very good way, she, she spoke to my brother and sister and that and explained things to them and I, I had a couple of friends that I spoke to and they sort of spoke to other friends to save me going through it all again and again, so that was good but it, now I'm actually sending out an email once a week to lots of, my friends and to Nathan's friends just with an update, a sort of a light-hearted update, but also getting the points across about washing your hands when you come in, don't come up if you're ill ...don't be offended if he tells you to get lost 'cause he's tired [laughs] ... all that kind of thing, but also saying how he is and how he's getting on with the treatment and, and I'm finding that very helpful for them, because they're not in touch with me so often and also for me 'cause it sort of vents for me as well. So I found that a really good idea to and I, I'm quite enjoying doing it ... **Jane***

For Jane, the initial phase of dealing with her son's leukaemia involved some sort of withdrawal from her social world due to the shock of his diagnosis. As a result of this, another member of the family took up the role of the informant (i.e. her mother). Finally, Jane found a way to share her son's news with the rest of their social world by sending an email weekly. This was less burdening and had a therapeutic potential for her. This first 'disconnecting' during the initial phase of the illness is indicative of the impact acute leukaemia has on family members.

Within this subordinate theme, family carers had to connect with their own self as well as their social circle. However, their efforts to socialise were not always successful. There are clear links here with the subordinate theme 'facilitating' (see section 6.6.2). These are the first signs of navigating in limbo.

6.5.2 Steering through the hospital environment

One of the major challenges family carers are called to deal with is the hospital environment. The acuteness of leukaemia forces them in a relatively unknown environment – the hospital – where they have to leave their family member to receive treatment. Carers need to feel a sense of security and safety in the hospital environment. The clinicians have to earn their trust, through addressing their varying information needs and through fostering a general feeling of

security that they would take the best care of their patients. Once carers feel that their loved ones were in 'good hands' they can 'let go'.

The level of trust and sense of security was deemed to be important by participants in the study. Trust in the clinical teams was not easily gained. A striking example of the significance of trust in clinicians and how it can facilitate their making-sense process is the experience of June:

*You know here are some lovely people in the Hospital and without them and the treatment that they've given him he wouldn't have been here, I mean he was ... you know ... and we really know that and some of the nurses on, they are fabulous [sniffing], em, and but there's always the case and they're often incredibly stretched and short-staffed and all the rest of it, em ... yeah ... you know, the bit that I do struggle with though is that with Ian's dyspraxia, living with other people is incredibly difficult for him, and sometimes when there's been an empty side room, they haven't given it to him and again I could have challenged them. **June***

At the beginning of Ian's hospitalisation June felt that more things could be done for Ian to facilitate his hospitalisation. Despite the credit she gives to the clinical team, she still questions their authority. Did they really do everything in their power to care for him? The fact that there is a small part of her not trusting the clinical team could hinder her making-sense process by adding a stressor that she felt urged to deal with (she took the initiative of asking for a second opinion).

The trust and the sense of security inspired by the healthcare professionals were vital for carers to be able to finally surrender their loved ones to the clinical team. Like June, it was not an easy task for Roy to accept that he had to entrust Mary's safety to someone else, but he had no other alternative:

*Just got to accept whatever the doctors tell you ... I mean Mary's really looked after here and it's, it's good because eh she had a really good doctor before Dr X and eh ... and he still, has popped in and is watching over her sort of thing and like what her course of action through her Consultant now and eh apparently Dr X's a very well respected doctor so em, so I think all the other doctors are sort of out to impress so they really look after Mary so it's, it's good, she's eh, she's looked after, so I feel good about that, I feel, I feel good that she's in eh good hands. **Roy***

There is a sense that Roy is not fully convinced of what motivates care providers to provide high quality care particularly in the adult hospital. He thinks that the new clinical team takes good care of Mary to impress the previous clinical team of the children's hospital. Early during the second interview he spoke of "doctors acting like robots" in his effort to describe the

mechanistic way they treated Mary during her bone marrow aspiration. This is expanded further down this section. Nevertheless, he still feels that in terms of expertise they are offering Mary the best possible care. This is how he can let go.

An important means of building the sense of trust and security was the provision of information. On certain occasions there was a discrepancy between carers' and patients' information needs. Clinicians failing to address that gap could provoke an additional source of anxiety to carers. For instance, Linda below describes this well:

*[Sighs] Yes we did, but em, I'm not sure that the information em ... was that clear. I think the medical staff seem to assume that you have more knowledge than you do have and you know the nurses just go about their jobs and finding, we never see a doctor, you really have to make an appointment to see a doctor, nobody actually tells you and Robert has been quite unwell so he's not capable of asking, he's, he's been, I think very quickly "institutionalised", so he lets it all happen and doesn't ask questions and you know the nurses come in and out and a few I ask and sometimes they, they don't know what it's for... But now, you know like the nurse I asked just now, she was telling me what it was for and how many hours it would last for so the information seems to be getting better the longer we're here, but it was a bit frightening that they didn't, they didn't communicate, I think that's the biggest problem, it's the biggest problem in life with human beings, we don't communicate. **Linda***

In this extract Linda describes how her need for information differs from her husband's. According to her, he had been "institutionalised", he observed things as they happened without having a say, without taking part in decision-making. She, on the other hand, felt an urging need to know the specificities of his treatment. After all, that was the only way to regain some level of control back. Within this extract, the role of the nursing staff in creating a safe and secure environment for the family caregivers is evident. Within the busy hospital setting, it can be a challenge to meet individual information needs. However, like Linda's case, addressing information needs has the potential of releasing family members from a significant amount of worry.

Roy acknowledged the fact that he had different needs to Mary:

The doctor comes into explain all these things and she's, she knows all these terminologies and things like that already, from the first time, and this time she's more like just, "Just get on with it," just, it's just, let's just do it ... which is fine and eh I don't, and she doesn't really want to know everything, everything this time, but I kind of want to know some of it, so like I've, I've gotten like some eh leaflets and stuff and, and

booklets from like the nurses and things like that and eh we recently got like a, a plan, the next plan of action, what's going to be happening for like the next, I don't know month or so, em so yeah I, I like to know maybe a little bit more than she's wanting to know right now, but that's only 'cause I'm new to it [mmm], I don't know as much as she does [mmm], eh though she tells me a lot, she, she explains these things to me as well and her parents are very good on the knowledge of things so they've explained a lot to me as well. Roy

Carers often realised they had more unmet information needs compared to the patients. The reason for this was primarily that in the health culture the patient is the main recipient of information that then he/she decides to distribute to the family. Another reason is the fact that information helps family carers to reduce their fear of the unknown and the uncertainty that dominates the limbo state. For this reason, Roy took extra steps, he read the information leaflets from Macmillan Cancer Support and he requested specific information from her clinicians regarding her treatment. Acquiring information and trying to understand how the treatment works was the way carers attempted to minimise the uncertainty, and thus facilitated their coping and subsequently making-sense process.

Pam, in contrast to Roy, wanted to have specific information tailored to Kevin's condition; for this reason they, as a family, just chose not to read any of the information leaflets they were given. They all made this decision consciously as a result of the trust they had in Kevin's care team. She speaks of the final unconditional surrendering to the experts' hands in the extract below:

Whatever Dr X and Y [nurse specialist] tell us is what we go by and, it's funny as well because they wouldn't say to you either, "And if you'd read your leaflet you would ah known that," [yeah], they're, you know em, to get the information like this that's specific to Kevin is better for us I think because the leaflets have to generalise the whole picture, and the same as when we got the leaflets for the drugs he was on, he just gave them to me and says, "Bin them, I'm not reading them," so, I mean maybe em it would help if you knew that, in advance that some o' these things could happen, but then there's so much information about what can go wrong as well that I think it's better not to [whispers] ... we just take it as, as they tell us. I think you get a lot o' confidence in them, he's been really well looked after now, after initially being disappointed by the GP practice, he's really been looked after well now. Pam

Pam whispered that "*it is better not*" to know everything regarding Kevin's leukaemia. Despite the fact that the interview was held in the privacy of her own home, she felt the need to lower the tone of her voice, as if she was sharing a secret. Fundamentally, she was confessing that

knowledge is power, yet it can bring a great amount of stress and worry as well. Surrendering her son to the experts was a way to manage the level of information received and eventually protect against the stress that this knowledge could provoke. This surrendering happened only after the clinicians gave them the confidence to act in this way. This is an important part of the process for family carers to find their way in the maze of limbo. Clinicians play a significant role because they provide the physical aspect of care (treatment and supportive therapies). Family members of patients with acute leukaemia are there to provide psychological and practical support, particularly in the early stages of the illness.

Similarly, Kirsty described the “way” that their Consultant approached them as one of the main elements of gaining her trust:

He's certainly given us the faith to know that he's going to cure him and I just, as I say obviously appreciate that so much and eh, I don't have any reason to doubt him, you know and I think that has come from him, although it could be anybody saying that it's just I think the way he does put it over to people and his openness and approach, being so approachable, because we knew we could go and ask him anything and ... and it did, it just made it, it made it easier you know just to deal with it all as much as you don't want to be dealing with it, it just made it easier to deal with and cope with ... so I think that's [...] I think just knowing that he's in such good hands, you know the people that are looking after him, I think that's, that's where our confidence has come from in the first place... the confidence that we've got in Dr X, and the way, as I say he ... spoke to us at the time and, you know reassured us and just told us everything, you know you, you just feel that you know what's going on, that he's not keeping anything from you or you know and everything's em spoken about and if we wanted to speak to him he's very approachable and ... as I say I think these have all helped, these things have all helped, and now it's just a case of let him get on and do his job and, you know eh ... [slight pause] ... yeah eh, I think that's been the biggest thing, to be honest, it's knowing that they know what they're doing, or feeling that they know what they're doing em ... because I think ...

CP: It makes you feel safe

C: It does, yeah, because if you felt that maybe they weren't being honest with you or telling you things, and keeping things from you, it would be totally different. No it's all, it's all been very positive actually em, as I say much as we'd rather not be going through it ... Kirsty

According to Kirsty, “the way” the doctor approached them included “openness”, “reassurance” and “honesty”. Family caregivers value themselves within the patient-doctor

relationship and it is critical that their loved one receives the best of care and support. The “way” in which the doctor related to them, repeated twice here by Kirsty, accentuates the significance and the difference this made for her. The presence of a care team carrying these values seems to facilitate carers’ navigating of the care trajectory and subsequently their making-sense process. In Kirsty’s case the doctor eased her fear of the unknown and built her confidence. Providing information to the family as a unit, being approachable and being honest were the main ingredients that provided the family unit with the feeling of safety and security.

There is an element that exceeds the physical aspects of care in the eyes of the carers; the ‘fragrance of care’ provided to their loved one. The fragrance of care refers to all the things that happen during human interaction that are not readily visible to the people who are interacting. This fragrance of care takes up different forms: for Kirsty and her family, it was “the way” the doctor spoke to them; for Roy it was the mechanistic manner the doctor performed a test on his wife (“doctors like robots”). June, in her second interview managed to put it in words by comparing the two hospitals where her son was admitted:

I feel quite different, it feels like I wake up in the morning and I can breathe again [...] so for me the lovely thing is that I walk into the hospital and I don't feel like I'm walking into a place where people are dying anymore ... and that feels a really big difference, em, it has quite a different feel, it's much more basic, it, but their attitude is somehow quite different [mmm], and I guess there are lots of younger people, they also want Ian to take much more responsibility than (Hospital One) ever did [mmm], they're straight away they're giving him his fluid chart to manage, em they've given him his drug chart, when he's too tired, he just gives it back to them [mmm], but they want you to take as much responsibility and work jointly with them, and to be able to say, “Come on, let's go outside,” and he just picks up his drip and we walk outside ... you can't really walk very far with a drip ... you can get some fresh air and, and it just feels more human [mmm], so yeah, so I feel much more positive. [...] Em it's funny, 'cause I was trying to ... describe to [partner] what it felt like and it was more like they gave me back the ability to think he's ... he's alive ... it's something about, when I used to walk into (Hospital One), and it's probably me not them, it always felt like I was walking into a place where people were dead and dying and there was this big thing, it was almost like they looked after people's physical health very well, but they forgot the person inside there ... and there's something about in (Hospital Two), there's a humanity there, and ... it feels really different, and I'm not sure what they're doing that's different, but it does feel like they've given me back a sense of “there is life here”. I don't know if it's any more safe than (Hospital One), and probably in some maybe (Hospital One) was safer, I have no idea, em I don't think there really was that much wrong medically there, but I think it's much more

about the model in (Hospital Two) is, it's about the person, and in (Hospital One) it felt like it was about the illness. June

June attached spatial meaning to each of the two hospitals she had visited; the one was full of death, while the other had life and hope. Her walking in Hospital One felt like she was walking in the valley of death. This happened for many reasons. To begin with, that hospital was linked with the shock of diagnosis. Also, Ian spent the initial phase (2 cycles) of his treatment there. The first cycle of chemotherapy (induction) is the most crucial and the most difficult for patients. June associated Hospital One as being the space in which her experiences of acute leukaemia materialised: her son was very ill due to the infection that followed the induction treatment; in his later treatment his body image changed (hair loss, loss of weight); and his dyspraxia was affected. Clinicians in Hospital Two had a different approach towards patients; this is why *“there is life”* there. In Hospital Two there was life for her son, as well as for her (*“I can breathe again”*) with the focus on fundamental, primary needs (being ‘human’, breathing as a sign of life). The first hospital carried the news of acute leukaemia, the loss of hope, while the second carried the restoration of hope. She makes the distinction between treating the individual person and treating the illness. The *“difference”* between the two hospitals (cited five times in the extract) is striking: in the first hospital the illness was *“the big thing”*. The fragrance of care refers to placing the individual at the centre of care, focussing on the person and not on the condition, or illness.

Dealing with the hospital environment can be a great challenge for family carers. Because they are not involved in the physical aspects of care, they need to know that their family member is receiving the appropriate care.

The second process identified was family caregivers navigating the limbo. Within this theme various elements were important: carers’ efforts to connect with their self and their social world and their engagement with the hospital environment.

6.6 Transcending limbo

The final process identified in carers' making-sense involved their efforts to transcend limbo. This superordinate theme included three subordinate themes, namely; coping, facilitating, and reconciling. These subordinate themes are subtly connected to the subordinate themes of the previous two processes. Carers did not always manage to transcend limbo, indicating the complexity of their making-sense process.

6.6.1 Coping

Carers employed a variety of different coping strategies, such as comparing and contrasting, living on a daily basis, being practical, maintaining normality, sharing, and being stoical. Not surprising their adaptation seemed to be influenced by how patients themselves coped with acute leukaemia.

One of the most common coping strategies carers used was to compare their current situation with previous difficult situations. This appraisal coping was a crucial element for their making-sense process. June below compared her previous experience as a carer with her current situation:

***June:** It's so different when it's your son, it just doesn't, it feels totally different, yeah.*

***CP:** Why?*

***June:** Because you expect, somebody that's 70 is, it's not that it's easy or nice but it's sort of much more natural to be supporting your mum when she's ill, than it is supporting your young son, it just doesn't feel right. And then you just want to take it and have it yourself, and for him not to have it. So, em I'm not sure that it did, it did help and my mum was a neurologist so she controlled em, kept in herself all her health stuff, I just helped her keep her day-to-day life really, whereas with Ian I've had to get much more involved ...*

June described how different and more difficult it was for her to be the carer of her own child. In her life she had this role for her parents, and this is why it felt so unnatural for her. It is a biological norm that the old die before the young; the children take care of their old parents, and so forth. This is why her maternal instinct appears in the form of a personal sacrifice in her

narrative: “*want to take and have it yourself*”. Then, leukaemia turns back into something vague (“*it*”), and sinister, a sign of a continuous internal processing.

At the beginning of her interviews, June shared how she coped with the prognosis of her son’s ALL:

*Em, I know he was really upset, 'cause he told me his dad came in one day and sort of said, “Why is he being so down?” you know, “He’s in remission and he’s cured and he will, in two years’ time he will be fine,” and of course ... it’s not the case, we hope he will, but the odds are very strong that it will come back. Em ... and I can’t get my head focus too much on that, or, you know in his head the odds are that in 5 years’ time he won’t be around, and I can’t let myself, so I’ve gone down into there too much, and actually it’s better to focus on what you have, rather than what might happen. And statistics can get it wrong, and he may be in the small ratio rather than the big ratio. **June***

The fear of relapse was lingering and June made a conscious decision to shield herself and focus on the present. For carers, living on a daily basis was a way to deal with the uncertainty of limbo. Roy explained this notion further:

*I just take it a day at a time, then my mind doesn’t get all [mmm] “buzzed” or just, I don’t get all ... I just, my mind works better that way [mmm], it’s easier to handle I think, a much better way to look at it, 'cause if you just, if you’re looking at, looking out into the future it just ... this process just seems a lot longer of getting her better, and it’s not a good way to look at it, I don’t think, so I think if you look at it like that it just looks endless. **Roy***

For Roy, thinking on a long-term basis “*looked endless*”. This phrase is indicative of the struggle that family carers are called to deal with in order to make the endless leukaemia journey more manageable. Roy shifted his attention to the current moment; by concentrating on ‘today’ he lifted the worry of ‘tomorrow’. Focussing on the present day and living on a day-to-day basis was carers’ best way to minimise the stress of the uncertainty and the fear of the unknown they felt when they entered the limbo state.

Furthermore, being practical was a way of regaining some level of control.

***Jennifer:** I don’t know I just eh ... em ... just thought leukaemia [laughs] ... just another, it’s an illness that has to be treated, yeah ... yeah. It wasn’t until em ... I suppose this sort of em urgency was to get him into hospital, be practical, you know get things done, get all the tests done, the bone marrow, and that’s, that’s, that was sort of going on, you know and over the next sort of few days, so it was just be practical, you know and just*

getting things done, and get him on treatment really [mmm], so yeah. I I, I just felt like Andy, I mean we just had to get on with it, m-mmm, so yeah ...

CP: *Is it easy then to be practical?*

Jennifer: *Yeah and I think partly because maybe it is because I'm a nurse as well [mmm], em ... yeah, probably ... probably, although you've made me think [laughs], em ... [?] yeah. I suppose it makes you feel that you're doing something.*

Jennifer's stoicism is striking in the above extract. Leukaemia was "just another illness" she had to deal with; therefore she focussed on sorting practicalities. Her nursing background might be one reason for her task-oriented coping. The fact that Andy had already been diagnosed with another serious chronic condition might explain her stoicism. The fact that participating in an interview "made her think" is noteworthy. Partaking in an in-depth discussion of the experience of living with someone with acute leukaemia can initiate a reflexive process, one which Jennifer experienced.

Carers' efforts to cope with the illness of their loved ones were not always successful. Pam decided to continue working despite her emotional and physical distress. She saw her job as a distraction:

Sometimes I'm just blubbing away in the kitchen, I could be doing my dishes and, and just start crying, em but I suppose they mean while at work and things, but it's not deliberate ... I'm not holding it in deliberately, it's just, that's just, just, you just go to work. I'm a disaster at work, em I'm not getting through the workload I would normally get through 'cause I'm finding my mind wanders and I've to go back and check that I have done that properly [mmm] and so things are a bit slower, but everybody's fine with that [whispers] "I'm there" [laughs] ... I'm going in, em so work's ... it's quite a nice distraction as well.

Pam

Pam's efforts focus toward masking her emotions even at her workplace. However, this masking did not stop acute leukaemia occupying her thoughts, leading to loss of concentration that eventually compromised her functional capacity to work and fulfil her role. Pam also used the avoidance strategy of shielding by hiding behind the word 'leukaemia', which does not include the term 'cancer':

And I think there's a bit of me as well that's not, and I mean knowing that leukaemia is the blood cancer, in fact this is a conversation I did have with M actually because we never use the word cancer, it's always leukaemia we'd say, and em I says to him, it is, it's, it's a funny thing but leukaemia and, and the word cancer is like ... ffft ... but, and

leukaemia doesn't sound as bad [laughs] although, do you know it's a funny thing, it's, and then I find myself just any time in the middle of the day it'll come in to my head, that you know it's, it's cancer he's got and that's a bit like ... [groans] ... it's, it's almost like if you say it's leukaemia it doesn't sound as bad, which is daft really but em, the word 'cancer' I think just fills people wi' fear doesn't it? **Pam**

The term 'cancer' has an intrinsic link to death, for some people, which she decided to ignore by hiding behind the word 'leukaemia'. However, these efforts to dissociate are obstructed by the reality coming back to remind her that acute leukaemia is a type of blood cancer. Choosing avoidance in order to cope with cancer, at least during the initial stages of the cancer journey (just after diagnosis and during the first treatment period), seems to be effective for carers for a limited amount of time.

Other family carers chose more active coping strategies to cope with acute leukaemia. For example, Roy and Mary chose open communication:

Trying to just say everything that's on our minds and just get it out [mmm], it feels better, so that none of us are keeping something in, hiding something from the other one [...] we find the, just eh full-on communication as much as possible helps the best [mmm], 'cause if I'm not talking about what's annoying me or, what's getting me down then it will just get worse [mmm], we realise that" **Roy**

From this extract, it seems that full disclosure of thoughts and emotions is an efficient way to deal with acute leukaemia. From Roy's extract it can be inferred that when they tried to avoid each other it was unhelpful for both. Open communication among family members can be difficult to achieve because it requires strong bonds to be present.

All the participants in the study agreed that patients' attitudes and adaptation to their illness was vital to determining the carers' own capacities to cope as well as contributing to their emotional status. For instance, Jane stressed:

... So I mean it's great that he's like that, it does make it easier on everybody else. You know people come up and they can't believe what he's like, just jumping about and, quite the thing ... he doesn't look ill at all – yet, I'm sure that'll get worse over the next few weeks but ... but just now it's copeable. **Jane**

Her son's positivity together with the fact that his acute leukaemia remained invisible for a while helped her cope. In certain cases, a positive attitude from the part of the patients towards their illness seems to give strength to the family members to also cope with acute leukaemia. The patient's coping strategy has a cascading effect on the carer's coping strategy.

However, this cascade of coping was not only prevalent in the participants of the study; as Jane explains below, “*getting on*” with acute leukaemia was really her only option:

*I think, you do find an inner strength as well that kind of prevents you doing the going down the worry, the “why me?” line, you just sort of ... I think it, 'cause it hits you before you've even had time to analyse it, you're in the throes of it, which means you're not actually having like a few weeks to sit and think about it, it's just, you know from the minute you get the diagnose, the next day you're in hospital and, you know and the adrenalin's sort of keeping you going, it's all just happening all at once and ... no I don't think you have time to think “why me?” or “why him?” or ... obviously I'd rather it wasn't him, but at no point have I, you know I'm not like “Oh, everything happens to us,” and I mean just now everything is happening to us ... the broken back stuff, my daughter's got a broken arm and I mean it's just like [laughs] ... but ... it kind of puts all that behind as well, I mean even a broken back's does, seems very trivial now [laughs] ... you've just got accept what you get and get on with it. **Jane***

Jane talked about finding an inner strength to move on, perhaps due to the lack of adequate time for retrospection. She did not have the luxury to dwell on the diagnosis. She was immediately set on a ‘fight-or-flight mode’, as mentioned in the entering limbo process. There was no time to ask ‘why’; she had to go with the flow of leukaemia (diagnosis, treatment, hospital visits).

To summarise, family carers employed a variety of different coping strategies to deal with the diagnosis of acute leukaemia. The coping style they will opt for may be affected by the quick nature of the illness as well as by patients’ own coping styles, thus further impacting on their making-sense process.

6.6.2 Facilitating

Carers’ primary concerns and actions in transcending limbo included facilitating patients’ lives. They utilised an array of actions in order to fulfil their role as facilitators, such as living on a daily basis, pursuing positivity, and being there for the patient. Interestingly, their most common technique was to mask their emotions in order to protect their patient. This emotional masking occasionally hindered their efforts to make sense of acute leukaemia. Several of these facilitating actions could be perceived as coping strategies, but because carers consciously used them to facilitate their family member’s illness journey they are presented in this subordinate theme.

As facilitating was their primary focus, carers in the study had to multitask in order to fulfil their other roles. This was particularly the case for the carers who were mothers. Jane provides a brief description of her new busy routine:

The first thing I do is get in touch with Nick [her son] and see how he is, em, I go out and get things that he needs, get his washing done to take it back up, em ... then, at the same time trying to keep things as normal as you can for the other kids, 'cause he's got 3 brothers and sisters, so you've also got to try and keep things really normal for them. Eh I also work part-time, so and if I'm working that day I've to get to work and then it's a case of rushing back to get the dog seen to before I can get up here in the afternoon ...

Jane

The role of facilitator, as undertaken by the caregivers, demands that the caregivers juggle with different roles. Jane's first priority was to contact her son and make sure that she addressed his needs. With most of her care circling around him, she felt she had to maintain a sense of normality for the rest of her family. Interestingly, when she explained this in the account she changed from the first person ("I") to the second person ("you") implying a sense of internal obligation she put on herself. Because she had multiple roles and responsibilities to meet, she was always in a rush with no time to think or pause. One of her needs, as she shared in the interviews, was to find a new routine that would include everyone: the hospital and the normality of the home for the rest of the family. This need to manage all these different responsibilities at once can increase the level of strain for the family carers. As she further explained, she needed to maintain normality for her son as well:

Well like my daughter is taking drama at school and she's a big production on which is the lead role and, didn't even remember to say, "Good luck," you know and you feel you're abandoning her, for the sake of another one which, you know so you have to try and ... I actually set reminders on my phone to remind me to say, "How did it go?" and things like that because your whole focus is on the one that's in hospital and you have got to keep things, try and keep things normal for the other ones and for, for Nick's sake because to me he needs to know that life's normal outside as well. [...] So it's, it's really just putting a big effort into try and keep things normal when you really don't feel like it.

Jane

Jane does not 'feel like keeping' things normal. Her new role prescribes that she retains a balance between her role as facilitator and normalising the rest of the family. The effort required to maintain the facilitator role is significant for the carers. This means that in order to facilitate the cancer journey of their loved ones, they may neglect personal needs and emotions. This self-neglect is further linked with the following subtheme of masking. Jane

again raised the issue of guilt when focussing solely on her carer role and neglecting her other roles. At this point in the extract she switched her narrative to the second person (“you”) once again, a sign of her inner obligation, the voice of consciousness. However, Jane was very creative in finding a way to remind herself of her other responsibilities as a mother. Maintaining normality as part of facilitating refers to offering patients the knowledge that life outside the hospital remains normal and awaits their return.

One of the major components of facilitating was family carers’ choice to mask their emotions in order to keep the focus on the patients and to retain a sense of balance in their relationship. This masking happened instinctively in order to protect the patient. Pam let her emotions out only when she left the hospital room:

Well it's going to be our life for the next 6 months as well so, it's, it's ... hard, so I try not to get upset in front o' Kevin, em and, and sometimes it's easy, you don't deliberately try and not get upset in front of him, it just happens and then when you leave him that's what it, you, you get a bit upset. Pam

In this extract, Pam’s emotional engagement is evident from her struggle to find the correct words to describe how she felt. Similarly, for June, putting up a brave face meant showing no emotion:

I don't know if it's putting up a brave face because yeah you cry and you do it at other times and he knows I'm upset but it is the feeling that he has got enough to deal with, he's having to deal with it, his life and we've talked about it. Em, and there was one night he talked really openly about ... he doesn't know, you know he was looking at his second opinion, a bone marrow transplant and he's sort of worked out, 'cause he does with research about how long his life is likely to be and he was talking about that and then saying that you know Dr X feels that he would do fine on chemo, but chemo is awful and there will come a point where he'll say, "I don't want any more," and I sat there listening because ... but then when I went home the next day [emotional and sobbing] then you let it out, but it's not, he's got enough em, he can't take responsibility for us, and his dad's just not coping at all, so Ian's having to be really protective and manage it all, em I'm sure he does some of that with me 'cause he doesn't want to upset me, but then sometimes he will have very open and personal conversations and he knows that I, when I'm being up and OK it's not because I'm pretending it doesn't exist, it's because you can't spend your whole life focussed on leukaemia, you have to, otherwise there's no real point in living, you have to look at and enjoy stuff and do stuff but I'm absolutely aware of the situation and he's very sweet. June

Masking was carers' ultimate way of protecting their loved ones. In June's case, emotional masking can be bidirectional: the patient protects the carer and the carer protects the patient. As June explained, her duty was to be there for him, to listen to him. She could not allow herself to be upset because that was not *her* time. *She* had to support Ian and not the other way round. She controlled her emotional response and let go in a more private setting. It is not surprising that at that stage during the interview June was so emotional: she felt safe and to let her emotions and thoughts out in the open after she had repeatedly forced herself to coat them in from of Ian. But this seemed to make her stronger; she took action and made things happen for him (seeking a second opinion). Showing her true emotions in real time would have hindered their communication. She chose to support him and, to do so, she separated this time and the time she would need to support herself to let go of her emotions.

As discussed in the navigating limbo process, carers' first and foremost concern is the patient. June further expanded on this premise:

*The whole way through the conversation I just thought I have to be here and listen to him because it's taken all of this for him to tell me and I have to be OK and the whole way home I just dissolved in tears and for the whole of the rest of the next two or three days, and I then I thought ... bummer this, eh we've got to do something about this and if he really believes that the bone marrow may be a solution, I'm going to make it happen, and so that's what I did. So I think it does both, it makes you absolutely fight for every bit that you can do, but then you have the other side where you just dissolve. If I'd burst into tears with him on that night, he would have then gone into making sure I was OK and not feeling he could talk to me, although I did say to him that I'm not just sitting here, of course I'm hurting like mad inside but you've got enough to deal with, without worrying about me, and I'll find my own way and place to let go of and get support from, 'cause he can't support ... he's so concerned about all of us, but actually he needs to know that we're OK, we're as OK as we can be and he needs to just focus on himself. **June***

The emotional masking served two more purposes in the above extract for June. Firstly, it preserved the focus on Ian; the fear of death did not turn to a fear of separation. Secondly, emotional masking kept the door to communication open. She provided Ian the space to express his inner thoughts and feelings and managed to retain the focus on him rather than her emotions or needs. In this way she hoped that their communication was preserved intact. Emotional masking takes effort to achieve; June was eating herself up inside, suggesting a different kind of emotional burden. Her "*dissolving*" could take up a literal meaning: her whole existence suffered from watching her son suffering from acute leukaemia. However, in June's case her professional background had helped her improve her masking ability.

The ultimate task of carers as facilitators is to be there for their relatives:

*I suppose my reason for being strong for Ian is he's got loads to worry about [sobbing]. I can still go home, I can go out to the pub, I ... I know there's nothing eating inside me, and I know I haven't got this thing ... hanging on me all the time [sobbing] and so ... and I know, part of my role is being there for him, but it, it has to be about keeping him calm and positive and so if I fall apart em ... I don't want him to have to fall apart even more than he needs to, and mums do... **June***

June, in the extract above, struggled emotionally (she was tearful). Accepting that the only thing carers can do is to offer their presence is very challenging. There seemed to be an internal battle between her need to express emotions and her duty to facilitate and protect her son from seeing her weakness. For June it added to her guilt: her son had so many things to deal with when she could still go home and be 'normal'. Leukaemia is "eating" him from inside, hanging over him, like another sword of Damocles². Acute leukaemia is seen as an illness that works from within, almost lurking and potentially bringing death. The fear of death remains continuously. She recognises that part of her role is being there to keep the links of the chain together, facilitating his journey. She guides her efforts to not fall apart, to keep everything in place.

Marion and Roy shared similar views of emotional masking and their need to be there for their loved ones:

*I, I really ... when I first heard, I thought it was so unfair, but then I thought I'm not the only mother that's grieving over something that's happened, and em there's no point in me, maybe I have a wee weep occasionally, but there's no ... it's not good for him if I resort to crying and weeping over him, you know. He knows that I love him and he knows that I will come up and see him and buy him nice fruit and juice and stuff like that, that I think is good for him, so... I've always kind of hidden what I thought sometimes, because I had a very lonely life when I first married [mmm] and em I just got on with it, you know. E-h ... it's probably part of my ... "me", you know, I feel it, but I don't want to eh, be crying over people or what and making them feel worse... **Marion***

*I just, all I can do is just be here, someone to talk to and just have fun with and ... that's all I can do, I can't do anything else. **Roy***

² In Greek mythology, Damocles had to eat his food with a sword hanging over his head from a single hair of a horse's tail.

Marion is normalising her response to her son's leukaemia. She went through a process of grief herself for all the losses of George: his health and the prospects of a future. Like every mother, she wants the best for her child according to her judgement. She also offers a link between the two elements of facilitating. She has to mask her emotional response in order to offer her presence. She is putting what is best for George above her personal needs. There is another element linked to emotional masking in her account: her personality. She attributes her need to mask her emotions to just being 'her'. Her life experiences had led to this choice. On the other hand, Roy's view on being there is linked with his feelings of powerlessness. It seems as though his words ("*all I can do*") weigh towards all the things he cannot do for his wife, as if his presence is not enough. Family caregivers might choose to mask their emotional response, either due to their effort to provide a normal (other than changed) attitude towards the patient, or due to unique personality characteristics.

A significant part for carers to transcend the state of limbo is their focus on facilitating patients' lives. To do so they need to find a balance among their various roles, to mask their emotional responses and be there for their loved ones. They try to maintain a level of normality at home with the rest of the family and at the same time they are the patients' companions in the cancer journey.

6.6.3 Reconciling

The final subordinate theme of transcending limbo identified from the analysis of the data was family carers' efforts to reconcile leukaemia. This subordinate theme comprised several different elements such as reprioritising, restoring balance, strengthened family bonds and self-awareness.

Of the more unusual aspects of reconciling was giving in to uncertainty; learning not to be in control of every aspect of life. June explained how she has surrendered to uncertainty:

And I think now that Ian and I are probably very good in not being in control ... and I think all of this has made, has made both of us in that situation and we're used to taking quite a bit of control in our life, even when it's difficult and not easy and when we, even when we haven't managed well, we've sort of managed and just now you have to sort of give up quite a bit. June

This type of reconciling requires additional strength, particularly for those individuals who were used to running an organised life. June “gave up quite a bit” of that control; she sounds almost satisfied with this ‘accomplishment’. While admitting that it is not at all easy; however, it can offer a sense of liberty once it has been achieved.

Acute leukaemia, on certain occasions, had reconnected the family. Kirsty shared how they were facing Stephen’s illness as a family unit:

*I think it's just, it's, it's a lot kind of deeper because you wouldn't normally have gone ... you know you wouldn't normally be dealing with something like this and, I think actually as well I've noticed Stephen maybe maturing a bit ... I think that, it's more just, there's a, a better understanding, maybe he realises again how much I've got on and you know with, just everything that's, and I think we have just probably developed a bit of a ... a more understanding, possibly. **Kirsty***

A life-threatening illness was the reason for them strengthening their relationship. Kirsty reckoned that her son understood her more now. Kirsty as a mother had to fulfil multiple roles, therefore in this extract she seemed content with this unexpected positive aspect of experiencing Stephen’s acute leukaemia. This was something she had not expected to happen. A life-threatening illness has the potential to bring families together, rejuvenate lost bonds and make people refocus on the core essence of human relationships.

Apart from the added depth in relationships, carers often saw life through a different lens, as demonstrated in Kirsty’s example below:

*I think it makes you think about life in a different way, you know when you've gone through something like this, you do realise what's important to you and I think you appreciate more, how ... you know things could have been so much different and eh, no I, I'm, I don't fear for the future, I'm just thinking positive, I'm not even you know, as far as I'm concerned he will be cured and I hope it will make him have a different outlook on life as well the fact that he's gone through this and I just hope that, like that he does what he wants with his life, that it makes him say well I, I realise you know, I might not have been able to do this so, that he, he just, yeah lives his life to the full. **Kirsty***

*I think for both of us it was like, you know what all these things, these stupid things that you argue about and other things really don't matter, ... I think from that point of, of view it's ... [slight pause] ... it has changed me a bit, I don't really know how, in what exactly, but, yeah ... **Kirsty***

Acute leukaemia, like other types of cancer, has the potential to change a person's perception of what is of value. Carers appreciated life more and felt that their loved ones (and themselves) would become better persons after the end of the leukaemia journey (leukaemia as a lesson giving experience). Kirsty, here, hoped that her son would live a fuller and more meaningful life. She hoped that as leukaemia changed her view of life, what is of most worth to her, that it could have a similar impact on her son as well. It is interesting how Kirsty described all the different aspects of change in her life, however she claimed that leukaemia changed her only "*a bit*" and she could not explain how. This perhaps is indicative of the fact that meaning-making is a complex process often occurring behind cognition and usually takes time and introspection to come to the foreground.

Similarly, Jane explained how trivial matters lose their significance after her son's diagnosis. Because of the speed that acute leukaemia took over their life, "*trivial*" issues were less important. She valued life more and saw things under a different light:

*Well I think, and in the sort of changing life it's like, suddenly other things are not important, like the car was needing fixed, usually that would be, "Oooh, I've got to get the car fixed, that's going to cost a fortune and ..." now it's just, we put it in the garage, get it fixed, you know it doesn't matter anymore, you know things like that just become insignificant really, you just ... you just realise there's more, more to life than, that these sort of trivial problems which were problems before, suddenly become ... was really not problems at all, you know ...it just kinda changes your outlook. **Jane***

Jane explained in this extract what she would classify as a "*problem*" before and after her son's illness. This shift in her perspective of the world bears almost an apocalyptic element: she could see things in their real dimension.

Much like valuing life, was finding inner strengths that, like June below, can help carers face their "*biggest fears*":

***June:** I think it's because, both for myself and for my son we've probably found a strength in ourselves and in each other that we didn't know we had. We've probably had to face biggest fears and come through them. Em, and I think it also makes you stronger about what's important to you, sort of the other stuff doesn't really matter, so it gives you a real strength of just what you're able to do ... yeah.*

CP: *Is it like re-prioritising?*

***June:** Em, totally, I mean things that used to bother you ... yeah everything you think about that's important to you in your life changes.*

CP: What is important to you?

June: I think being alive and family and people. Em, money is not ... it doesn't mean a thing anymore, yes it can help pay for things that you need but actually it's irrelevant. Em, I think it's the people around you, yeah. And I suppose also taking every tiny little bit of life that's good, so going to do things which you would normally enjoy seems much, much, much more enjoyable, but it's one of those highs you then notice the lows much more, that you do appreciate em, and spending time with people who are important, I think really has changed. [...] It is really precious and even when he was really ill on that first cycle and was just lying there, and he'd wake up and we'd play a game of cards or something, those moments all felt really pressured ... pres-, precious, not, not pressured, I suppose there was pressure there, but yeah, and then yesterday just getting Ian out of hospital and going for a meal somewhere, I mean you, you notice those times much more, whereas before they felt every day, and ordinary, which was nice too.

In order to manage the adversity of a life-threatening illness, June had to gather her inner strength, a strength, as she ascertained, was unaware of possessing. In this extract she speaks for both herself and Ian (“we”). Being able to confront and manage this difficult situation gave her a sense of accomplishment that perhaps helped her see what was important in her life and eventually facilitated her transcending of limbo. June’s new priorities included the value of life (being alive) and the value of family (being with people she loved). At the same time, money had almost no value; she perceived it as a means to an end. She used to value work, but not anymore. It is of interest that she corrected herself (“pressured” – “precious”) when describing her time with her son: a hint that she was still in the process of navigating the limbo. Like patients’ assimilating of acute leukaemia, family carers follow a similar process of reconciling that involves a reprioritising of values and beliefs. It is the nature of a life-threatening situation that shatters people’s core assumptions and values that leads them to re-consider what is truly significant in their lives. This reprioritising of values helps to accommodate acute leukaemia in their new lives.

Another example of this process is Roy, who appreciated life more. He understood the fragility of the human body. The previous belief of invincibility had given its place to being more aware, appreciative:

I appreciate things ... more. Em ... so I just ... em probably mostly life's so fragile, you forget how eh ... my mum told me the other day and put it into, sort of an interesting way just like eh, we don't really appreciate of how fragile the body is and how you could just disappear at any moment... now Mary's got leukaemia again but you live in fear that she's not going to get better ... and it is quite a strange thing, why your perspective

changes and you think, you think like that now, I mean you didn't think like that before. When I was younger I was really accident-prone, 'cause I thought I was basically invincible, doing such stupid things and breaking a, lots of bones in my body over the years, but eh, I was just sort of a fearless kid when I was younger, now you sort of like appreciate that, we're frag-, very fragile people and ... and I just want her to, I just want her to get better and for it not to come back ... 'cause I want, I want us to just live our entire lives and I want us to continue to appreciate just how much, well just everything we have and ... yeah I think I'll be a better person after all this. I'll appreciate people more. Roy

Roy was still young when he was called to support his wife in her acute leukaemia journey. He came to question one of his core assumptions about youth and invincibility, while at the same time he started to appreciate the fragility of human nature. In a sense his wife's illness matured him. In this extract he seemed to go down the path of introspection and reflection: it was *"a strange thing"* the change in his perspective. At the end he is almost making a promise of becoming better after the end of Mary's treatment. A life-threatening illness such as acute leukaemia can impact on family carers by forcing them to live in the present, valuing what is already acquired, and lessening their worries of what could have been.

What is more, acute leukaemia initiated a process of self-awareness for some of the carers. June, for example, learned to face her biggest fear and got to know herself better, finding strengths she thought she never had:

What does it mean about me? Em ... I think it means that I've got to know myself really well, and I've found strength in ways that I didn't ever know I had. Em ... because I would have expected to be on the floor crying all the time and I have been physically on the floor crying and hysterical but I know that I can get up and I can keep going [...] I think that's, made me much stronger, but there's a separateness to me in all of that, and I think it's only once I'd really gone through what is this, how, how is this really, really for me? [mmm], and what's happened, I'm sure I'll come out of it different and stronger, and already as far as work and what I do em, you know I used to work lots with carers and carer's organisations and arrange their funding and spend time with them, I realise I had no idea what it really felt like [mmm], I thought I did. June

In June's account there are signs of personal growth; her son's acute leukaemia made her *"different and stronger"* changing her self-identity. She explains the aftermath of her experience, as she still in the middle of the journey. For June that was experienced as a *"separateness"* implying that although she is accompanying her son in his leukaemia journey, she does not understand completely the repercussions this co-travelling has on her as an

individual. Yet, the signs of the transcendence are clear. Family caregivers' can potentially find positive aspects within the experience of acute leukaemia. These can be seen as early signs of having made sense of acute leukaemia.

The final process through which family caregivers made sense of acute leukaemia was transcending the state of limbo. Elements of this process included the coping strategies carers utilised, their focus on facilitating patients' lives and finally, their efforts to reconcile with the changes acute leukaemia brought into their lives.

6.7 Chapter summary

This chapter presented the findings from the family caregivers' dataset. Analysis revealed three distinct making-sense processes from those of patients'. Family carers made sense of acute leukaemia through entering, navigating and transcending a state of limbo. The state of limbo resembles a maze where carers find themselves in. The invisible nature of acute leukaemia creates difficulties to conceptualise it, however, they experience its impact on their lives quite hastily. From this point they navigate limbo, through socialising and learning how to engage with the hospital environment. The third process identified, transcending limbo, involved their various coping mechanisms, their attempts to facilitate the cancer journey, and finally, reconciliation.

CHAPTER 7 – Discussion, implications, and conclusions

7.1. Introduction

This PhD study aimed to explore how individuals – patients and family carers – make sense of acute leukaemia within the first year of its diagnosis or relapse. Data analysis from a total of eighteen participants (ten patients and eight family carers) revealed two different sets of making-sense processes. For patients, the three processes included decay, transformation and growth with an ultimate purpose to maintain a state of equilibrium. For family carers, the sense-making processes involved entering, navigating and transcending a limbo state. This chapter will discuss these findings with the wider literature on patients with haematological malignancies and their family carers as well the wider meaning-making literature. The study's strengths and limitations are also detailed. Finally, recommendations for future research and clinical practice are discussed and overall conclusions are presented.

7.2 The tree of equilibrium

In order to answer the first research question – ‘how do patients make sense of acute leukaemia?’ – ten patients with acute leukaemia were interviewed on two occasions. Findings revealed that, as patients learn of their diagnosis and their treatment commences, they seem to undergo three different processes in order to make sense of their illness. Within the process of decay the negative aspects of nine subordinate themes were presented, such as having an impaired self and feeling like a prisoner. Decay was the most prevalent of the three processes, perhaps due to the fact that interviews were conducted during a stressful period for patients (most of them were near their original diagnosis or the diagnosis of relapse) when everything seemed to happen too fast for them to have the time to reflect upon their experience. Nonetheless, there were also signs of a transformation process taking place. Transformation, as a middle state process, is characterised by its changeability, either to the direction of decay or to the direction of growth. Therefore, elements within transformation could present more subtly. For example, in the subordinate theme of ‘leukaemia in disguise’, patients started to create mental images of leukaemia in their attempt to understand it. The final making-sense process was growth. In the process of growth the positive elements of the identified subthemes, such as strengthened family bonds, and reprioritising values, were apparent.

Because interviews were conducted at a time when patients experienced extreme anxiety, this process was the least expressed. These three processes were conceptualised within the metaphor of a tree of equilibrium. As a living organism, the tree is always moving towards a homeostatic status: the equilibrium. This complex process of nature depicts precisely the complex mechanisms of the meaning-making process. In this section, each of the three different processes are discussed; at first as a whole within the wider literature regarding meaning-making. Then, for representation purposes, each subordinate theme manifested in the three processes is discussed within the relevant literature of cancer and/or haematological malignancies.

Findings from this PhD study illustrate that these three processes occur in a simultaneous manner, that is to say decay, transformation and growth do not follow a successive clear-cut order. To explicate this, certain aspects can demonstrate signs of decay, when others are transforming and others are growing. The ultimate goal is to preserve a state of balance – the equilibrium – that the diagnosis of acute leukaemia has disrupted. This co-existence of processes is indicative of the inextricable way meaning-making occurs. It has been postulated that the meaning-making process is linear, consisting of overlapping phases [161]. In their meaning-making model, Park and Folkman [11, 14] identified a number of distinct categories of making-sense processes, such as automatic and deliberate, or assimilating and accommodating. As analysed in Chapter 5, the three processes identified in the current study are consistent with all of the distinctions proposed by Park and Folkman [11, 14]. For instance, within the processes of transformation and growth there were signs of assimilation and in certain occasions, signs of accommodation, where patients' illness affected their global meanings. Similarly, patients were not always aware of the meaning-making processes taking place, thus supporting the existence of automatic processes too. Yet, patients also made more conscious, deliberate efforts to cope with acute leukaemia. As this PhD study was a qualitative exploration of patients' making-sense processes, mapping the exact nature of the relationships between the themes within each process was not appropriate. However, what this PhD study permitted was an in-depth exploration and interpretation of these processes that offered the opportunity to gain a better understanding of the highly complex nature of making sense of an illness such as acute leukaemia.

The importance of looking into the processes patients use to construct meaning in the context of a life-threatening illness has been highlighted in the relevant literature [11, 231, 412]. Research has also focussed on exploring and addressing patients' search for meaning in the context of end-of-life care [252, 278]. Findings from this PhD study share commonalities with processes described both in the end-of-life context and in the early stages of cancer. Based on

three domains (assumptive world, sense of coherence, meaning-based coping), Lethborg et al. [278] share the idea that patients go through a dynamic process in order to make sense of their advanced cancer. This process involves positive reappraisal and revision of beliefs and goals. The authors argue that their proposed model is both 'linear and fluid' and stress the idea that as illness progresses, new issues may derange the balance [278]. The three processes of decay, transformation and growth share this idea of linearity and fluidity. On the one hand, there are different elements present in all three processes in one instance, thus implying that these processes co-occur. On the other hand, for an element to move from decay to growth it must go through transformation and vice versa from growth back to decay, thus implying a linear process. Similarly, there are two sense-making processes identified in patients with colorectal cancer: disorientation and reconstruction [260]. The phase of disorientation resembles the process of decay of patients with acute leukaemia, while the process of reconstruction has elements of both transformation and growth. Researchers identified internal and relational factors that can impact on whether patients will move towards transformation and growth, proposing that the pathways are different for different people [260]. This conceptualisation of meaning-making is in accordance with this PhD study's findings of maintaining a state of equilibrium within the three identified processes.

Participants of this study went through a process of decay before they could move into transformation and eventually growth. Of significance was the fact that within the process of transformation, due to its ever-changing nature, elements could trigger decay as well as growth. This tendency has been documented elsewhere: the process of meaning-making can be distressing and does not preclude that meanings will be made [203]. For patients with acute leukaemia this contextual nature of meaning has been supported as the meanings made (as an end product) are always dependent on persons' values and experiences at a given point [51, 52]. Patients' sense-making can also transform and grow, indicating the existence of positive aspects within the experience. The idea of post-traumatic growth even during the initial phase of patients' illness, for example, has been documented [413]. Similar results have been reported for patients with breast cancer, whose meaning-making was described as part of reframing the illness experience [257]. Also, results from the qualitative thematic synthesis conducted as part of this Thesis suggest that accommodating acute leukaemia through reprioritising values and finding meaning is an integral part of patients' efforts to build a renewed self [68].

Findings from this study highlight the specific characteristics of acute leukaemia that make it hard for patients to understand. Of particular interest was the fact that one of the most prominent signs of decay was acute leukaemia's disguise as infection. The majority of the

participants commented on the initial invisibility of the illness. Leukaemia's trait of invisibility was previously reported [3, 74, 75, 153], and further supported by the experience of early flu-like symptoms as well as the requirement for several referrals before a definite diagnosis can be made [49, 76]. This partly explains why the diagnosis came as a body blow for participants. This sense of blow escalates as everything is put on fast-track mode: hospitalisation, intensive chemotherapy, supportive treatment. At the same time, the rest of the person's life is put on hold. Previously, Koehler et al. [74] stressed that the invisibility of acute leukaemia was a factor that hindered patients' coping processes six weeks after their diagnosis. A recent Canadian study concluded with similar findings; to highlight that the illness came 'out of the blue', the authors described the initial phase of learning the diagnosis like 'being abducted by the illness' [413]. This feeling of rapid overnight transition from health to illness, and body blow, was also reported by patients with breast cancer after receiving results from routine testing [253]. Within the process of transformation patients started to perceive their acute leukaemia more as an individual illness and formed mental images of what their cancer looked like. Familiarising themselves with the medical terminology was also an important part of their sense-making within the transformation process. However, their difficulty to make sense of leukaemia remained.

After receiving the diagnosis of acute leukaemia, treatment initiation is imperative. Not only do patients have to deal with the news of the diagnosis and subsequent treatment toxicity, but they must also endure prolonged hospitalisation. One of the unique findings of this study was how participants perceived their hospitalisation as a state of imprisonment. This sense of imprisonment depended on the dynamics within the patient-doctor relationship and was present in all three making-sense processes. At the initial stages of treatment, participants focussed on how restrictive their illness was and that they had to spend the majority of their time within their hospital room. Somewhat similarly, in two previous studies, patients explained how their world gradually shrunk in a hospital room [77], and how this felt like being abducted and taken to an alien place [413]. Cohen et al. [414] also described that despite patients accepting the necessity of isolation, they nevertheless experienced it as 'claustrophobic' physical and emotional confinement. Following this phase of decay, the patients' perception of imprisonment started to transform. Patients may be isolated, yet they may also feel protected in the cocoon of the hospital setting [210], much like Emma described in the current study's findings. As time elapsed, patients in the current study seemed to get used to the idea that their hospitalisation was only temporary and had a purpose. They began to familiarise themselves with the previously unknown hospital environment. A new routine emerged that involved aspects of their new life in the hospital (i.e. treatment, socialising with

other patients and hospital staff). It has been postulated that patients, who manage to find meaning during their hospital stay, experience time as passing more quickly; therefore, the sense of imprisonment and institutionalisation subsides [45]. Of additional importance, the trust in the healthcare professionals proved to be an important aspect of how patients in this study went through the process of growth. Forming relationships with healthcare professionals has been described as being important to facilitate adjustment [415], and enable patients' making-sense [260]. This sense of trust and security has been linked to patients surrendering control and choosing to have limited information [413]. McCaughan and McKenna [258] described the complexities of how newly diagnosed patients with cancer processed information and made sense of their cancer. The initial stage of learning the diagnosis involved a shutting down of information due to the trauma experienced. However, as time passed, patients sought information by berry-picking from multiple sources, including health professionals, lay persons, and peers [258]. Information-giving has been viewed as a balancing act [416, 417] and the approach taken to deliver this information is important for patients' meaning-making [418]. In that sense, the focus needs to be on how patients might need different levels of information: some will need more; others will need less.

A number of different coping styles were identified during the analysis that participants employed in order to make sense of acute leukaemia. Coping has been defined as a person's efforts to manage demands 'appraised as taxing or exceeding resources' (p. 141) [127, 128, 230]. Lazarus and Folkman [127, 128] were the first to describe coping as a cognitive emotional process, but since then research in the area has revealed that this is a much more complex process affected by the environment, its demands and resources, as well as by personality characteristics [230, 419, 420]. One of the early works regarding coping strategies in the context of cancer revealed that distancing was the most commonly used coping style among 603 patients with mixed cancer diagnoses in different phases of illness [421]. In the current study, three negative coping strategies were used by patients within the process of decay, namely denial, avoidance and distancing. Participants did not necessarily use these three strategies exclusively; rather they interchanged them with others identified within the processes of transformation and growth. There is evidence suggesting that patients with acute leukaemia employ different coping strategies, which, in several cases, contradict one another [72, 75, 78]. This finding is also consistent with previous research suggesting that patients with leukaemia may use maladaptive coping styles, such as choosing to keep a distance from the situation or adopting more fatalistic attitudes [71, 72, 74, 77, 78] in an early attempt to cope with their illness [74, 210] and maintain some level of control [74]. However, avoidance coping has been associated with negative meanings of the cancer experience [266]. Patients' coping

strategies can also transform in order to further adjust to acute leukaemia. By using old frames of reference, patients in the current study compared and contrasted their illness experience with previous difficult situations and chose to change their strategies if they deemed them to be unsuccessful. On many occasions, participants appraised their previous coping strategies as ineffective; this facilitated the transformation of previous behaviours to accommodate the new reality of leukaemia. Indeed, it has been argued that, in order to make sense of their illness, patients feel the need to fill the gaps in their newly formed understandings [49]; they achieve this by recalling previous experiences of their cancer treatment [49], and by drawing upon other people's experiences of cancer and contrasting them with their own situations [258]. Patients' coping started to show signs of growth, when they began to embrace more active and positive strategies. Participants in this study mentioned that remaining positive and hopeful was crucial to help them deal with their illness. In Coolbrandt and Grypdonck's study [63], patients described this as writing a positive story. This finding is in agreement with previous research in mixed samples of patients with haematological malignancies [209], patients with acute leukaemia [68], and patients with colorectal cancer where positive thinking was a strategy employed to help these patients make sense of their experiences [260]. Acknowledging their personal influence, adopting a positive attitude or a fighting spirit by working through difficulties, as well as taking action, which involves adaptation and acceptance, have been cited as the most common positive coping styles [71, 72, 74-77]. Of interest is the stoical attitude some participants in this study adopted towards their experience of cancer, which both supports [253] and contrasts [62, 422] previous findings. Indeed, whereas in the study of Bohemke and Dickerson [253] patients described their illness as something one had to deal with, Bulsara et al. [422] and Saleh and Brockopp [62] reported that patients maintained a fighting spirit or a positive attitude, respectively, to actively cope with it. Of interest is the fact that whereas religious coping has been identified in the literature as a coping style used by patients with acute leukaemia [51, 52, 68], participants in this study made no references to their faith. It can be hypothesised that for the absence of similar findings, culture might have played a role. Indeed, evidence suggests that belief, religious affiliation, and attendance has seen a significant decrease in Britain, while during the 20th century there has been a rise of 'fuzzy fidelity' (a term to describe a person neither religious nor completely unreligious) in Europe [423-425]. Finally, results from the qualitative thematic synthesis presented in Chapter 1 suggest that hope has a buffering role in facilitating patients' coping process [68]. Patients in this study explained how by remaining hopeful they managed to cope with their illness. This finding is also in agreement with evidence derived from studies among patients with mixed haematological malignancies [48] and other types of cancer [426].

Regardless of making-sense process, the physical repercussions of treatment for leukaemia were evident as particularly challenging in the patients' accounts. In his philosophical works, Merleau-Ponty [353] was the first to argue that through experiencing bodily aspects of an illness, a person creates meaning of his/her experience with the illness itself. He referred to this as 'embodiment' [353]. Features of embodiment were also observed by participants in this study. Specifically, having to deal with fatigue and infections was a frequent statement, and patients found these as the most distressing side-effects in the overall treatment experience. It can be argued that fatigue is one of the most commonly reported symptoms associated with cancer and its treatment [427-431]; indeed, fatigue has been identified as the overall bodily sign of cancer [256] and cited as the most important aspect of QOL [35]. Moreover, as a sign of infection, fever has been cited as one of the most frequently reported symptoms in patients with acute leukaemia [36, 56], whereas febrile neutropenia related to cytotoxic chemotherapy is also common in patients with haematological malignancies [432, 433]. As time passes, patients' physical status starts to improve; hence, the experience associated with the physical impact of leukaemia can be seen as subject to transformation and potentially growth. Growth within this theme of embodiment relates to patients becoming 'experts' by apprehending a new language. Indeed, patients in this study learned a lot of unknown terminology during their hospitalisation, which then they took up and used in their accounts. This was also reported in a German qualitative study [75], where patients with acute leukaemia used the new terminology without, however, necessarily understanding what it meant. Yet, these patients were interviewed within the first week of diagnosis, which to a certain extent can justify their initial lack of understanding. In the current study, as time passed and the illness became more visible, patients could recognise symptoms and treatment side-effects; a similar finding was reported in a sample of women with ovarian cancer [254].

Participants expressed an array of emotions during the interviews that were seen as part of the decay process only. A reason for this might be related to the timing of their participation in this study: all patients were interviewed either close to initial diagnosis or close to relapse. During this initial phase, the shock of the news combined with fear dominated their minds; this was followed by uncertainty and a sense of living in an unreal world. These emotional responses were signs of their decaying emotional world, and are consistent with current available evidence on emotional reactions to initial diagnosis, including shock and disbelief [49], anxiety, anger, fear, and grief [260, 262]. In the context of breast cancer, women also described the 'surreal feeling' of dealing with their diagnosis [253]. Dealing with uncertainty regarding diagnosis, treatment expectations and prognosis has been already reported [3, 262], and can be of particular importance depending on the type of leukaemia in terms of its impact

on QOL, with acute leukaemia generating an immediate life-threatening feeling [47]. Participants revealed additional emotions that included feelings of guilt, embarrassment, depression and loneliness. Similarly, feelings of isolation, or even abandonment, have been consistently reported for patients with lymphoma [415], mixed haematological malignancies [210, 434], oral cancer [255], colorectal cancer [260] or mixed cancer diagnoses [262]. In the current study, these feelings may be exaggerated by the restrictive nature of acute leukaemia. What is more, in results from a recent study on a large sample of patients with acute leukaemia (n=205), researchers concluded that 32% of the population sample had some form of acute stress disorder [43], confirming the findings of the current study. Embarrassment, as expressed by the study's participants, might be associated with health-related stigma, which has been investigated in patients with breast [435], colorectal [436] and lung cancer [437] and can increase psychosocial morbidity [438, 439].

An illness such as acute leukaemia can bring a number of significant changes to the person [434], one of them being how the patient views his/her self. During the process of decay, two subthemes were identified, 'blaming the self' and 'the impaired self'. Like George in this study, patients may blame their previous lifestyles for developing cancer [260, 261] and, in fact, there has been evidence supporting the idea that self-blame can act as a mediator between cancer-related stigma and adjustment [435]. In agreement with existing evidence [253], patients might find their old self erased due to physical and emotional changes, and replaced by a new impaired and vulnerable self. Roing et al. [255] described how patients with oral cancer viewed their self as being captive to a changed mouth, diminished and stripped off their social world. Similarly, in women with recurrent breast cancer, this impaired new self was linked to a perceived loss of personality and identity [259]. In this subordinate theme, transformation occurred more subtly. Patients in this study guided their efforts towards preserving their old version of self, and quite often they compared their old self with the altered version of self that leukaemia created. In a similar fashion, Evans et al. [262] describe the vulnerable self and the strong self, the new self and the old self. Patients may act towards either going back to the old familiar self or embracing the changes and accepting the new self [262]. Such signs of growth were also made apparent in this study, where a new, better version of the old self evolved, one that is more spontaneous, and full of pride for facing acute leukaemia. In survivors of haematological malignancies, positive changes in patients' sense of personhood were reported, including how they viewed themselves and others, by being less judgemental, feeling more confident and having a sense of achievement after surviving a life-threatening illness [50].

As a restrictive cancer, acute leukaemia can have a ripple effect on patients' social world [68]. A social world in the process of decay can have different ramifications. Participants in the study stressed how their social world shrunk, creating feelings of alienation. The significant impact that cancer can have on patients' loved ones emerged as a major theme in a qualitative study conducted among patients with mixed haematological malignancies [280]. Patients acknowledged the supportive nature of interpersonal relationships, but often felt that people close to them could not fully understand them [280]. Burles and Holtslander [254] also reported communication difficulties with the social world among women with ovarian cancer, whereby pre-existing problematic relationships were exacerbated by the experience of illness. In the current study, patients' social world was observed as being in constant change from decay to transformation and over to growth. Acute leukaemia did affect the roles patients had in life; however, this transformed balance in their interpersonal relationships also influenced the way they reacted to this state of imbalance, and how they managed their interactions, so that patients began to eventually understand leukaemia. Campbell [415], in her study, also described a transformative nature of social world for patients in protective isolation, where their efforts were guided towards building ties with the outside world. Within this subordinate theme the process of growth was illustrated particularly when patients described how their interpersonal relationships had changed in a positive way. Participants also spoke of the supporting environment created around them, and how this contributed to their efforts to cope with their illness. Previous studies have indicated that sharing the cancer journey with the family can be vital in affirming relationships, strengthening bonds, 'reinforcing the importance of the family' [50], and fostering hope [51, 62]. In addition, Tang et al. [260] reported that external/relational factors including the family and social network were deemed to be just as important in the patients' making-sense process.

A considerable part of the decay process that patients in the current study experienced was occupied by loss. Acute leukaemia, similarly to other types of cancer [254, 255, 435], was understood through the various types of loss it imposed upon the person: loss of normality, loss of control, loss of independence, and loss of future. Loss of normality may be perceived as a disruption in the previously exercised way of living [254], possibly stemming from the realisation of the loss of one's own health (described as a body blow) and independence [255, 259, 262]. Closely related to this type of loss are the impact of cancer on personal relationships [262] and a sense of alienation from people [278] which may be seen as additional losses that patients are faced with. To visualise the magnitude of the associated loss, Nissim et al. [413] referred to it as 'abduction'. As a consequence, patients may struggle to gain control of the situation. The idea of loss of control in patients diagnosed with acute leukaemia has been

previously documented [74]. Persson et al. [440] concluded with one theme very similar to the decaying process, where loss of control completely took over patients' lives. Boehmke and Dickerson [253] reported that women with breast cancer understood their illness through their perceived losses, and this enabled the initiation of a process of grief. All efforts to maintain normality and to replace uncertainty with some level of certainty and control in patients' lives are part of a transformation process. For the study's participants this transformation process seemed to be an integral component of making sense of acute leukaemia. Their focus was equally guided towards maintaining their normality and regaining control. McCaughan and McKenna [258] identified that the final stage of dealing with information was taking control over the situation, a process that can vary depending on individuals' previous experiences from the initial stages. Being able to maintain the normality and control over patients' lives involved a process of growth. Some patients managed to maintain their normality, as they were allowed by the nature of their treatment plan. This is consistent with previous findings from a qualitative study where patients guided their efforts to regain control by establishing the equilibrium with friends and family [422].

Participants' efforts to assimilate acute leukaemia were present in the processes of transformation and growth. Within the process of transformation, the assimilation was demonstrated through patients' realisation of their mortality and initiation of reprioritising personal values. Consistent with previous findings on patients with cancer [256, 259, 441], a life-threatening illness such as acute leukaemia can initiate a reflective process in patients regarding their own mortality. This introspection may lead to a process of re-evaluating goals and personal values. This finding is in agreement with evidence from studies conducted in patients with haematological malignancies [51, 416, 434], and in the wider cancer context [202, 254, 259, 260]. Moreover, participants in the current study stressed how their experience of acute leukaemia made them see their life from a different perspective. Accepting the unexpected in life [260, 279], appreciating the present moment [254, 279] by attributing meaning to trivial everyday activities [276], looking for the positive impacts of cancer by developing a positive attitude towards living with cancer [279], finding new meaning through benefit finding [254, 260], and embracing the coexistence of gain and loss [260] have all been cited in previous studies among patients with various types of cancer. Accommodating the illness in a person's life story consists a significant element of the process of growth, and, according to Park and Folkman's meaning-making model [14], is indeed the final result and goal of the process of making sense. Particularly for those participants whose acute leukaemia had relapsed, the belief that they had been given a second chance to live through having spent time as survivors was apparent. Among twelve long-term (3-15 years) survivors of

haematological malignancies, McGrath [50] reported that patients were mindful of the “gift of extra life” (p. 285) that the treatment had offered to them, which they consciously honoured through living every moment to the fullest [50].

7.3 The maze of limbo

In order to answer the second research question – ‘how do family caregivers make sense of the illness of their family member?’ – eight family caregivers were interviewed on two occasions. Analysis of the findings revealed three distinct novel making-sense processes of acute leukaemia: entering, navigating and transcending a state of limbo. The limbo was presented in the visual form of a maze (Figure 5, Chapter 6) in order to highlight the sense of unknown threat that characterises it. Hence, family caregivers in the initial process of entering limbo were called to identify and explore the various impacts that acute leukaemia had on their lives. Within this process, the sense of disorientation was compelling as they struggled with conceptualising the illness due to its invisibility. The next making-sense process included family caregivers navigating limbo, where steering through their social world and the hospital environment comprised their main activities. Finally, the third process involved carers’ efforts to transcend limbo through coping, facilitating and reconciling. Carers did not always manage to transcend limbo, indicating the complexity of their making-sense process. The intrinsic elements/subthemes within each of these processes do not necessarily develop sequentially one after the other; however there are connections among them, accentuating the complexity of family caregivers’ sense-making process. In the subsequent paragraphs, the overall making-sense processes are discussed as a whole and then each subordinate theme identified within each process is considered within the wider literature.

This is the first study to qualitatively explore how family caregivers of patients with acute leukaemia make sense of the illness during the phase of intense treatment; therefore the findings are unique. A significant part of limbo has to do with managing the uncertainty that the illness brought into their lives. Uncertainty has been reported in spouses of patients with haematological malignancies [442] and breast cancer [443]. In the study of Wilson et al. [442], the experience of BMT was described as ‘riding a rollercoaster in the dark’ (p. E17), while Harrow et al. [443] explained the experience of breast cancer in a similar way as ‘living in limbo’ (p. 351). However, in the current study, the maze of limbo was described as a core element of the meaning-making process of carers, where they enter, navigate and optimally,

transcend. A qualitative study in a mixed sample of family caregivers suggested that their making-sense process consisted of three elements: expectations, explanations and strategies [295]. As carers created meaning, each of these components influenced the other [295]. Yet, in the current study, part of carers' efforts to make sense related to apprehending new roles, shifting from being a family member to being a 'carer'. In fact, because of the nature of acute leukaemia (patients are hospitalised for the greatest part of their treatment), their role was more to facilitate than to provide physical care (such as bathing) to their loved ones. Finally, elements of the three making-sense processes are also present in the expanded model of Fletcher et al. [15] on the cancer caregiving experience, and the integrated meaning-making model of Park and Folkman [11, 14]. In particular, considering the Fletcher et al. [15] model, the subthemes of entering and transcending limbo share commonalities with the various elements within the stress component. The second process of navigating limbo also shares some common ground with the contextual component of the model, where the participants had to steer through their social world and the hospital environment. Similarly, caregivers' efforts to conceptualise acute leukaemia are consistent with processes regarding searching for comprehensibility [11, 14]. Nevertheless, it must be stressed that this study did not aim to test or confirm/reject any of these models.

Within the first process of entering limbo, the conceptualisation of acute leukaemia was evident from five aspects, none of which follows a linear order. These elements included carers' descriptions of the journey towards receiving the diagnosis, feelings of shock, the need to find a cause for the illness, mental images of leukaemia, and finally their difficulty to conceive and understand acute leukaemia. Carers' efforts to conceptualise leukaemia were not always successful. The fact that leukaemia can be invisible prior to diagnosis, with hardly any signs to warn carers for the imminent shock, was one major barrier to caregivers' efforts to make sense of the experience of transition from good to ill health in their loved ones. In attempting this transition, carers felt the need to describe their initial encounters with the healthcare system. Schaepe [143] also reported on patients and carers' joint journeys to reach the diagnosis of haematological malignancies through their encounters with medical system. Realisation of the diagnosis came in two steps: intellectual understanding when the diagnosis was announced and emotional realisation occurring later when treatment commenced. In conjunction with leukaemia having no known cause, carers in this study were also faced with the major difficulty of shaping their own explanations of why leukaemia happened. In the study of Pakenham [217], carers of people with MS employed causal explanations in their efforts to make sense of the illness. Still, little is known as to how carers create explanations, and views remain controversial on whether attributing a cause to illness has an impact on

finding meaning, as, according to Pakenham [217], merely attributing a cause to a negative event does not necessarily translate into finding meaning. In his study in caregivers of patients with MS, having an illness with a specific cause facilitated their making-sense process [217]. Another element which participants in the current study used in their efforts to conceptualise leukaemia was verbally describing their mental images of the illness. Accessing mental representations of illness has been identified as having a therapeutic influence by changing behaviours, psychological outcomes and recovery [444-446]. Existing research is limited to patients with breast cancer [191, 447]; further research in the field examining mental images of family caregivers of patients with cancer is needed.

Also in entering limbo, carers in this study described how acute leukaemia impacted on their lives. Specifically, leukaemia was experienced as 'rocking' their lives, thus turning everything upside down in an instant [141], much like opening Pandora's box [448]. Losing track of time and sensing the world as unreal were described as dominating aspects of the new reality. The intensity of such reactions can be attributed to the acuteness of the circumstances associated with the diagnosis and treatment of acute leukaemia, which might be one of the unique experiences in the population of family caregivers, and warrants future investigation. A cascade of emotions, including feelings of powerlessness, loss, fear for the lives of their loved ones, and uncertainty were also reported, emotions that eventually led to overwhelming distress. Such findings are consistent with previous research, suggesting a range of similar and additional emotions (such as despair or hopelessness) in carers of patients with haematological cancers during BMT [140, 448]. In an IPA study of young people's accounts on their experiences of dealing with a diagnosis of cancer in their parent, the threat of loss of the parental relationship and the potential death of the parent was clearly evident [297]. This may well lead to caregivers experiencing a host of (frequently unmet) social and psychological needs [140]. Through accompanying patients, caregivers in this study also found their selves in a state of physical deterioration. Fatigue, sleep disturbances and cognitive dysfunction are only some of the symptoms previously reported among caregivers of patients undergoing BMT [140, 141], and in the wider population of family caregivers of people with cancer [92]. In a longitudinal study of patients and their family caregivers in the context of BMT, depression and anxiety were higher among the caregiver group, supporting the idea that the multi-tasking demands placed on them can have a negative impact [86]. Disruptions in the daily living of caregivers, which has been reported as highly prevalent in the context of treatment for leukaemia [10], can be regarded as a potential cause for elevated physical distress and subsequent health deterioration. In spite of the lack of substantive evidence that link cancer

caregiving to compromised health [5, 449], family carers have been described as living in a situation of overall traumatic crisis [146] that affects multiple domains of their lives.

As past research has documented [38, 448], the perception that the locus of attention should remain with the patient came naturally for carers in this study. This often led them to suppress their own potential emotional and physical distress, which further increased their burden. For carers to recognise the fact that they themselves needed support was not an easy task. Nevertheless, in the subordinate theme 'steering through the social world', the two main elements identified related to carers' needs to be supported and their efforts to connect with their wider social circle. These elements have played a significant role in their sense-making process. The social isolation and the disrupted family relationships affected by the experience of the patient's illness have been cited as in the caregiving journey [141, 142]. For some carers, having been able to talk to their family and friends was beneficial, while others thought of seeking more professional support in the form of counselling. Other sources of support such as peers [297] and the community [92] have been also reported. These were the first signs of navigating in limbo. Carers in the current study attempted to connect with their own self as well as their social circle. However, their efforts to socialise were not always successful. In an earlier study, spouses of people with acute leukaemia or lymphoma described that receiving support was dependent on the availability of their social network [146]. As a barrier to effective socialisation, relocation has also been postulated as having an impact on how new social relationships are created that can potentially result in further feelings of stress and anxiety for carers [148].

In order to navigate the maze of limbo, family carers in this study were called to deal with the hospital environment. The acuteness of leukaemia quickly forced them into an unfamiliar environment, which they strived to understand through finding their own place in it. In the past, family carers accompanying patients to the hospital commented on how they felt like 'bystanders' in the whole situation [143], how they spent considerable time waiting in uncertainty [448], how their presence next to the patient might not have been always recognised [146], and how they needed to adapt to the healthcare system in order to find their role in it [450]. Because they could not be directly involved in the physical aspects of care, caregivers' need to know that their family member would receive appropriate care was also pressing. In order to feel secure that their loved ones were in 'good hands', carers expressed the need to rely on trustworthy clinicians and receive accurate, adequate and reassuring information. The lack of and expressed need for additional information for family caregivers has been stressed in previous research in the context of cancer care [10, 145, 451]; therefore, the findings of this study are consistent with existing evidence.

In the third making-sense process identified, the transcending of limbo, carers employed a variety of different strategies in order to cope with the patients' acute leukaemia; these included comparing and contrasting, living on a daily basis, being practical, maintaining normality, sharing, and being stoical. Research in the domain of coping of family caregivers of patients with cancer is underdeveloped. Gaugler et al. [452], in their study in a small sample (n=52) of caregivers of patients with cancer, concluded that the use of negative coping strategies, such as worrying, were correlated with negative psychological outcomes, like role entrapment, emotional fatigue, anxiety and guilt. Given the paucity in research related to the coping mechanisms of caregivers of patients with haematological malignancies, these findings are unique and have several implications for clinical practice (see Section 7.5). Of note, seven out of the eight participants were women. Moreover, for some caregivers their adaptation seemed to be influenced by how patients themselves coped with the illness. It is only recently that researchers have shifted their focus towards examining the process of coping with cancer from a dyadic viewpoint, through reciprocal influence [5, 15, 92, 93]. So far, evidence from studies on couples' adjustment to cancer support the idea that there are indeed more factors that interplay in the coping process [15, 92]. Fletcher et al. [15] suggest that couple communication can be one of the main elements that can regulate meaning. This is consistent with findings from a study on spouses of patients with leukaemia or lymphoma, where the initial crisis of the illness was processed according to the relationship already established within the couple: either as a unit equally, or as a unit independently, or separately with the spouse having subordinate role [146]. However, evidence so far comes from studies on couples; further research is warranted in the field to explore other types of caregiver relationships, such as parents and siblings.

Family caregivers in this study focussed their efforts to transcend the state of limbo around facilitating patients' lives. In doing so, they utilised a variety of different of actions, such as living on a daily basis, pursuing positivity, and being there for the patient. Informal caregivers of patients with cancer have been identified in the literature as balancing a host of different roles and tasks [5, 140, 141, 453]. One of this study's novel findings, the act of facilitating, involves a number of practical tasks from the part of the carers, which, according to literature, is deemed to be an important part of social support for patients and has been associated with increased survival [42, 454]. The demanding nature of the new roles family caregivers are facing has also been documented in the context of BMT [140, 455]. Carers need to be present for their family members in order to feel that their role was achieved or to enhance personal connection has been documented in spouses of patients undergoing BMT [442] and in the wider cancer context [5, 92]. A novel finding of this study was carers' use of emotional masking

in order to facilitate patients' journeys, which occasionally hindered their efforts to make sense of acute leukaemia. Carers, in masking their emotions – occurring instinctively as an act of protection – maintained the focus on their loved ones and retained a sense of balance in their relationship. In the context of haematological malignancies, a somewhat similar finding was described by Schaepe [143] when family caregivers tried to contain their emotional responses regarding the news of the diagnosis in front of the patients. This type of emotional masking could be interpreted as part of 'protective buffering', a specific type of relationship-focussed coping [87, 93, 456, 457]. According to Langer et al. [87] this is a technique employed by both patients and caregivers, and spouses in particular. However, in this study the majority of the carers were mothers (n=4), which implies the presence of a maternal protective instinct. In any case, as evidence remains sparse within this domain, further research examination of the type of relationship and protective buffering is needed.

The final element in the process of transcending limbo included family caregivers' efforts to reconcile leukaemia by reprioritising, restoring balance, and strengthening family bonds. The fact that participants in this study identified positive aspects in their experience of having a loved one diagnosed with acute leukaemia during a stressful period (close to diagnosis or relapse of illness) is worth highlighting, given the fact that the majority of evidence on family caregivers focusses on the more negative aspects of the cancer experience [122, 140, 458, 459]. Research in the wider cancer context has shown that family caregivers report enhanced relationship closeness [460, 461], that relationships were strengthened [106] and valued more [303, 304]. Furthermore, in the context of other serious illnesses such as MS, family caregivers made sense of the illness by perceiving it as a 'catalyst for change' in many life domains, including setting new priorities and goals [217]. Particularly in the context of haematological malignancies, Beattie and Lebel [140], in their review, found only two original studies [462, 463] focussing on the beneficial aspects of caregiving in the context of BMT, such as personal growth and an enhanced relationship with the patient.

7.4 Study strengths and limitations

This PhD study has a number of strengths worth highlighting. First, this is the first study to focus on the making-sense processes of patients with acute leukaemia during the phase of intensive chemotherapy treatment. Given the fact that the majority of the existing evidence comes from the context of transplantation, this study provides evidence for the first time on

how patients make sense of their illness during a very stressful period of their cancer journey. Second, this is the first study to include family caregivers of patients with acute leukaemia and explore their sense-making processes. Despite the fact that caregivers of patients with acute leukaemia are called to deal with the numerous impacts of the illness on their lives, research in this field is underdeveloped and is primarily focussed on spouses of patients with haematological malignancies in the context of BMT [140]. Third, the fact that the population of this study was limited only to patients with a diagnosis of acute leukaemia as a first instance and not as a subsequent diagnosis of myelodysplastic syndrome or chronic leukaemia, increases the value of the findings regarding this population. The researcher made this effort in order to address the problem reported in the literature of studies being conducted in diverse haematological population samples. Fourth, the method used to collect data has been particularly efficient considering the context of this study. By using serial, in-depth interviews with patients during their period of hospitalisation when they received intensive cytotoxic chemotherapy, the richness of the data obtained was secured and, at the same time, the possible burden from the interviews was contained. The time between the two interviews was enough to allow participants to reflect on their experience while at the same time adequate for them to be able to recall what was discussed. Finally, the study employed a novel approach to analyse the data (i.e. the IPA approach). Considering the fact that IPA was initially developed for the field of health psychology, its use in different disciplines such as nursing has only lately started to accelerate. Moreover, its use in this particular population of adult patients and their carers is considered novel; so far it has only been used in the context of haematological malignancies during childhood [464].

Despite the study's contribution to the current body of evidence, there are also some limitations worth considering. First, the patients participating in the study were approached either close to their initial diagnosis or their diagnosis of relapse. This means that the homogeneity of the sample, as advised by Smith et al. [352], was somewhat compromised due to the specificities of the population group. Ideally, patients would have to be close to the first occurrence of leukaemia; however, the inclusion criteria were relaxed to include more possible participants. Second, there are few gender-related issues to consider regarding the sample of the current study. The patient group consisted primarily of men ($n=7$), while the family caregiver group consisted predominantly of women ($n=6$). In light of this division, it might well be that these processes are indicative of how adult men with acute leukaemia and women family caregivers make sense of the illness. The fact that acute leukaemia is more prevalent in men than women might be an explanation for this tendency, however, including more women in future studies is necessary to tackle their making-sense processes. Similarly, in the family

caregivers group there were more women, in fact, mothers, participating than other family members or other persons significant to the patient. Again, these making-sense processes identified might be more relevant to women caring for adult patients with acute leukaemia. According to Romito et al. [6], the resulting profile of the caregiver being female (usually spouse, middle-aged, Caucasian) is due to the sampling process, where patients are the ones identifying their caregivers. Third, the educational background of participants in both groups was considerably high, with the majority (n=12) having college/higher education. As a result, these participants may have been able to articulate better their thoughts and experiences. Also, in two occasions family caregivers (Jennifer and Kirsty) had received nursing training, therefore it is possible that their initial understandings and meanings could have been informed from their professional experiences. Fourth, the fact that two patients had co-morbidities – Andy had MS and Bruce had heart disease – could have potentially influenced the way they experienced and made sense of acute leukaemia. Their coping strategies, for example, might have already been forged by their previous chronic conditions. However, both of Andy and Bruce went on through a process of comparing and contrasting, similar to the process that other participants had followed when facing stressful situations, somewhat compensating their previous illness experience. Due to the restrictions of the tight timeframe of this PhD, as well as the difficulties in recruiting participants, it was not possible to add further criteria to exclude people diagnosed with acute leukaemia with co-morbidities, therefore findings are interpreted with caution. Fifth, this study was conducted in two health boards in Scotland, and all participants were of British ethnicity. Culture is an important factor that has been said to impact on the formulation of global meanings and later on their attribution of situational meaning to their experiences [11, 232]. Therefore, findings from different cultural backgrounds could have produced different narratives and, therefore, different findings. Sixth, it is acknowledged that the serial interviews, although ensuring richness of data, could have played a role in the meaning-making process itself; that is to say, offering the participants the opportunity to tell their story may have enabled initiation of a making-sense process, engagement to which might not have occurred before the interviews took place. However, it has been argued that one way to reach meaning is through narrating a story [343], and, as Smith et al. [352] admit, there is a double hermeneutic that is normally part of an IPA study: the interviewer trying to make sense of the interviewee trying to make sense of an experience. Seventh, the structural organisation of the making-sense processes identified (the tree of equilibrium and the maze of limbo) represent the interpretation of one researcher. Others could have organised these themes and processes in different ways. However, as stated in Chapter 4, an audit trail throughout the research process, and particularly in during the analysis process, was kept to clearly demonstrate how the researcher

reached to the formation of these superordinate and subordinate themes. Finally, these findings are from a specific group of people affected by acute leukaemia under certain circumstances, therefore, the making-sense processes described are rather more suggestive than conclusive. It is important to acknowledge the fact that this study was only able to provide a 'snapshot' of acute leukaemia and the meaning-making processes people utilise to accommodate the illness in their lives. Yet, the philosophical underpinnings of this study helped to compensate for this, by supporting the notion of multiple aspects of reality. As the context and circumstances will change, there is an expectation that the participants' meaning-making processes will develop as time passes. As it is described in Section 7.6, further research is warranted to further examine how meaning-making processes change over time, and also to investigate these findings in larger populations.

7.5 Implications for clinical practice

The findings of this study have several implications for clinical practice. Clinicians could take valuable lessons regarding how to (a) manage the invisibility of acute leukaemia, (b) enhance trust in healthcare professionals, (c) enhance patient autonomy and address the impact of isolation, (d) facilitate the making-sense processes of patients and their caregivers, and (e) increase public awareness of haematological malignancies. These implications are presented here.

An important finding of this study was that the invisibility of acute leukaemia obstructed participants' making-sense processes, particularly during the phase of induction treatment. The need for clinicians to be aware that patients are more vulnerable during the period after diagnosis was also stressed from the qualitative thematic synthesis [68] presented in Chapter 1. Interventions aiming to minimise the perceived invisibility of leukaemia can be beneficial for both patients and family caregivers. Along these lines, the provision of comprehensible information targeted to individual needs is paramount. For the patients, this involves targeting the process of decay and facilitating their move to transformation, whereas for the family caregivers, this involves targeting the first process of entering limbo, and facilitating their navigation through it. Clinicians need to assess patients' and caregivers' understandings of the current situation and also repeat these assessments frequently, especially during the initial phase of the illness where everything is unknown. By minimising the fear of the unknown, clinicians can set the grounds for establishing rapport with patients and families. A good way to facilitate the provision of information is with the use of visual aids, either in the form of printed leaflets or with the use of technology. Acute leukaemia comes along with a new terminology that patients may take on board without necessarily understanding what it means

[75]. Using familiar vocabulary, pictures, and three-dimensional visuals to explain the physiology of blood and what happens when someone has acute leukaemia can be one way to make the illness more tangible and visible. It may also be useful to discuss how patients would prefer to inform their families, as well as how to phrase and explain their diagnosis and treatment. In this way, caregivers' initial feelings of disorientation can be lessened. Nevertheless, it is also important to remember that patients may not always want full disclosure at the beginning of their cancer journey, as they may find it overwhelming [413]. Healthcare professionals should acknowledge this reluctance of patients to receive information that often is too complex for them to process at that stage. At the same time, family caregivers may have different information needs from patients. Therefore, it is elementary for clinicians to distinguish and differentiate the required level of information needs and act accordingly in a sensitive manner.

Both patients and carers in the current study stressed the significance of having trust in their healthcare professionals. For instance, a clinical team that could inspire feelings of security and safety was crucial for family caregivers to 'let go', while they emphasised the 'fragrance of care' that the hospital environment infused. Building a trusting relationship with patients and their families is highly recommended for clinicians involved in their care [413]. Such a relationship and interaction presumes a high degree of skilled communication that involves active listening when engaged in dialogue, including skilfully guiding the patient's or carer's expressions of thoughts, feelings and emotions, while at the same time being aware of their own responses to expressed needs [465]. Learning such communication skills should be addressed within education as part of undergraduate curricula [466]. There is a need for healthcare professionals to master multiple qualities such as being sincere, being able to detect emotions, and being able to express genuine interest in patients [467]. Equally, it is of importance to provide adequate emotional support to healthcare professionals, in order to enable them to cope with the information that such communication endeavour can yield. As a result, offering some level of clinical supervision to professionals where such levels of intense communication are required is essential in preventing emotional burnout [466].

It is acknowledged that because of the acuteness of the illness, patients and families have little say in choosing between treatment options. For patients with acute leukaemia, surrendering control to the clinical team has also been reported as an adaptation strategy in order to manage the initial shock of a life-threatening illness [413]. Research also suggests that patients with haematological malignancies might prefer a more passive role in decision-making [10, 49, 73, 154]. In this sense, the clinical teams are perceived as 'powerful others' to whom patients give permission to take control of the situation [413]. However, whether this 'surrendering' is

actually beneficial is debatable; patients in the current study had a strong sense of imprisonment due to their hospitalisation that involved feelings of powerlessness rather than adaptation. Preserving patients' autonomy and including them in the decision-making process is important even in the face of trivial tasks as it makes a difference to their perception of control during their hospital life [68, 468, 469]. Prolonged hospitalisation also resulted in feelings of isolation for some patients of this study. There have been several suggestions on how to manage these emotions, such as music therapy, which has shown good results in minimising anxiety in prisoners [470]. In patients with cancer, a positive, yet small in size, effect on mood has been reported following varying music therapy interventions [471]; however, evidence remains inconclusive with regard to post-intervention effects on patient anxiety [471, 472]. Moreover, promoting exercise in order to manage fatigue has been examined in patients with acute leukaemia [32-34], showing some promising results in patients in protective isolation. Another, perhaps easier implemented, way to manage isolation is to promote peer support within the hospital environment, working around the phases of total aplasia. Living with acute leukaemia can be a very personal experience; however, sharing this experience with other patients who have also had similar experiences can be beneficial. Similar arguments can be made for the family members too. Offering access (physically or by phone) to patients and their families who have survived the illness can have a comforting impact on both patients and their loved ones [466].

An important element to consider from the findings of this study is facilitating patients' move from the transformation process to the process of growth, as well as aid family caregivers to navigate and transcend limbo. Building a trusting relationship was one way of working towards this direction. Helping patients to identify their old frames of reference can enhance their ability to make sense of acute leukaemia [68]. Additional factors have been proposed in the relevant literature that can play a role in the process of meaning-making, thus suggesting possible areas for intervention. Such factors include intrusive thoughts [264], personality characteristics [264] and additional stressful life events [268]. Interventions aiming to enhance patients' capability of managing the various cognitive and emotional challenges of the illness and increase their resilience by rebuilding strengths through adversities are recommended. For example, giving patients the opportunity to talk through their thoughts and emotions can be an effective way to facilitate meaning-making. Having a psychologist as part of the multidisciplinary team may be one way to address this need. Similarly, family caregivers might need additional support. For example, in the UK, the presence of local Maggie's centres in the proximity of large hospital organisations is becoming more common. Informing caregivers and patients on the availability of such support may be the first (and, in fact, in some cases the

only) step required for people to acquire the already existing services that are available for them.

Finally, participants in the study stated that their previous knowledge of leukaemia as an illness was very limited. In fact, they all considered it to be a childhood illness ('this is what children get'). There is, therefore, a clear requirement for additional efforts to be made in order to increase public awareness for all haematological malignancies. The organisation of open days through University initiatives could be a useful first step to engage and inform the general public, as well as give the opportunity to survivors of acute leukaemia and their significant others to share aspects of their experiences. To this end, the contribution of haematological malignancies-dedicated charities such as Leukaemia and Lymphoma Research in UK (<http://leukaemialymphomaresearch.org.uk/>) would be paramount.

7.6 Implications for future research

Opportunities for future research are also highlighted by the findings of this PhD study. Such areas for investigation are discussed in detail hereafter. First, with regard to the qualitative thematic synthesis presented in Chapter 1, because evidence regarding patients with haematological malignancies remains scarce and is usually presented for the population as a whole, it would be interesting to bring together the experiential evidence on patients with different haematological illnesses, such as multiple myeloma. The added value of a meta-synthesis of studies already conducted can highlight the current gaps and indicate under-investigated areas that researchers could focus their interest on, as well as inform clinicians of the particularities of these populations.

Patients with haematological malignancies still comprise an under-investigated population when it comes to understanding the illness experience [68, 153]. Therefore, there is an explicit need for more exploratory studies in this and other haematological populations, such as patients with chronic leukaemias and multiple myeloma, in order to explore their illness experiences and particularly their meaning-making processes. Similar suggestions can be made for the populations of family caregivers of people with such cancers, whose experiences still remain widely under-researched. This study was one of the very few conducted on family caregivers of patients with acute leukaemia, and the first to specifically look into their meaning-making process. The findings presented in this thesis highlight the multiple impact of

acute leukaemia in their lives. The dearth of evidence on this specific population has been documented and the need for further research has been already stressed [68, 413].

Despite its cross-sectional design, this PhD study revealed an array of meaning-making processes in people living with acute leukaemia that may be interrelated and interchangeable. It would be interesting to investigate how patients' and/or carers' efforts to construct meaning change over time and are influenced by concurrent life events. Hence, the need for dedicated longitudinal studies is evident. Such prospective, repeated-measures (quantitative) and multiple interviews (qualitative) studies could be designed to follow patients and/or caregivers over a period of time (e.g. during the first one or two years post-diagnosis), and collect data at important time-points of the cancer journey (e.g. at diagnosis, at treatment initiation and continuation, during survivorship or close and after relapse) not necessarily mapped to the treatment changes.

Data collected in the current study were analysed following an IPA approach. A core element of this type of methodology is its focus on idiographic accounts of participants. As stated in Chapter 3, this method does not lend itself for comparative analysis [373], that dyadic data would require. However, as per the recruitment method there are seven paired cases of patient-caregiver dyads (mostly mother-child) that that can be further analysed using a different approach at a dyadic level to investigate whether there is a dyadic meaning construction. For the purposes of the current study, comparisons between the two groups (patients and caregivers) were avoided in order to preserve the idiographic nature of the IPA methodology. Since dyadic studies are currently being developed [15], specifically examining the interaction and impact of cancer on spousal relationship [88], it would be interesting to examine the impact of different types of patient-caregiver relationships on the meaning-making processes.

One of the issues highlighted in Chapter 1 referred to inadequate sampling procedures in the current studies on patients with acute leukaemia. For instance, in several cases, sample sizes were insufficient to provide the power necessary to support inferences. Although to a certain extent this is reasonable due to the overall low incidence rates of leukaemia, multicentre studies could potentially provide a mechanism to tackle this methodological issue and boost recruitment rates. In conjunction with conscious recruitment efforts, the possibility to achieve sample diversity, including equally represented groups of male/female or younger/older patients, as well as others from diverse cultural/ethnic backgrounds, would also increase. Thus, space could be created for comparisons between groups of patients with different

demographic characteristics that would allow the examination of possible latent influences on the different meaning-making processes.

Finally, this study can form the basis for a following meaning-making intervention. Future researchers not only need to target this particular group of patients, but also their significant others in order to test interventions and address their rising (and, at times, concurrent) needs. For instance, one of the important findings of this study was the initial difficulty of both groups to conceptualise acute leukaemia due to its invisibility. Studies capturing the issue of mental representations of illness would be useful as they could help clarify how people conceptualise their illness. Interventions that utilise visual aids to provide clear information early in the diagnosis of acute leukaemia could exert significant effects on patients' and/or carers' efforts to make sense of their situation, and eventually facilitate psychological adjustment in the long run [204]. Another possible way to support patients and carers in finding meaning in their experiences of acute leukaemia could be through testing interventions that allow visual representations of mental images of illness, such as art therapy. As a psychotherapeutic approach, art therapy "uses the expressive qualities of visual mark making ... to effect personal change with the aim of increasing well-being and psychological functioning" (p. 135) [473]. Indeed, there is preliminary evidence indicating that art therapy might be a useful adjunct to facilitate coping with the illness [474] and express emotions [473]. It is reasonable to hypothesise similar effects on sense-making too; future research is thus warranted. Such interventions would require the use of combined approaches and methodologies. According to the revised MRC framework for complex interventions [475], the development phase of an intervention includes conducting a literature review and developing a theoretical model to ground the intervention. In this sense, this PhD study can be seen as the first step to the development of a future meaning-making intervention that will focus specifically on patients with acute leukaemia and their family caregivers.

7.7 Conclusions

Patients diagnosed with acute leukaemia face a multitude of different challenges due to the acute nature of their illness, which usually requires prompt initiation of cytotoxic chemotherapy treatment. Equally, their family caregivers are called to deal with the sudden onset of an invisible illness and to steer through their various roles, including dealing with the

hospitalisation of their loved one. Nevertheless, evidence continues to be restricted on how this particular population – patient and caregivers – makes sense of acute leukaemia. This first attempt to provide an in-depth exploration of processes, through which people affected by acute leukaemia create meaning, fills some important gaps in knowledge in the relevant literature.

By using a novel methodological approach in these populations, that is to say IPA, important unique aspects of how patients and carers made sense of acute leukaemia were gleaned. Findings from the patients' dataset revealed three experiential processes that occurred concurrently: *decay*, *transformation* and *growth*. Participants described aspects of all three processes, each to a different extent, supporting the idea that even at the initial stages of the cancer journey there are elements that transform and grow as well as decay. The process of *decay* encompassed more negative aspects of the experience during the meaning-making process, such as acute leukaemia coming in disguise and patients feeling like prisoners. *Transformation* was characterised by its changeability, either to the direction of decay or to the direction of growth. *Growth* contained positive elements of sense-making, such as strengthened family bonds, and reprioritising values.

This study also revealed for the first time the meaning-making processes of family caregivers of patients with acute leukaemia. Three different processes were identified: *entering*, *navigating* and *transcending limbo*. The state of limbo was conceptualised as a maze in which carers find themselves. In *entering limbo*, the invisible nature of acute leukaemia creates difficulties to conceptualise it, however, they experience its impact on their lives quite hastily. In order to *navigate limbo*, carers have to steer through their social world and the unfamiliar hospital environment and, eventually, they *transcend limbo*, by employing various coping strategies, facilitating the cancer journey of their loved ones, and finally by reconciling with the illness.

What the findings of this novel study underscore is the perplexing nature of the overall making-sense journey for both patients and family caregivers experiencing acute leukaemia. Additional longitudinal research will be required to not only confirm (or reject) current findings, but also to shed light upon the various ways in which meaning is initially constructed, negotiated, re-visited and reformed as patients and/or family carers go through the different phases of living with the illness. Meanwhile, there is a strong requirement for adequate and on-going support to be provided by clinicians so that patients and carers visualise the 'invisible' acute leukaemia and make sense of their illness-related situation that favours their short- and long-term psychosocial adjustment.

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Appendix 1. Published Work

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The experience of acute leukaemia in adult patients: A qualitative thematic synthesis



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ABSTRACT

Keywords:
Cancer
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Thematic synthesis

Purpose: The aim of this review was to systematically identify and synthesise all qualitative evidence on how adult patients diagnosed with acute leukaemia experience living with their illness.

Methods: A systematic search strategy was developed comprising of two search strings: i) acute leukaemia and ii) qualitative methodology. The search strategy was run in seven electronic databases (Medline, CINAHL, PsychINFO, EMBASE, BNI & Archive, SSCI and ASSIA). Nine qualitative studies in adult patients with acute leukaemia, published in peer reviewed journals between 01/1990 and 01/2013 were included in the final sample.

Results: The qualitative thematic synthesis resulted in the development of a conceptual model describing a person's path to build a renewed self. Following the initial blow of diagnosis with the range of initial reactions, patients with acute leukaemia are living in a contracting world; they have to deal with the life in hospital, the several losses and the impact of their illness on their emotions and interpersonal relationships. Several factors take up a buffering role at that stage: coping, support, information and hope. Finally, patients accommodate acute leukaemia in their lives through re-evaluating personal values and assigning new meaning to their experience.

Conclusions: Results from this thematic synthesis are indicative of the impact of acute leukaemia on patients' lives and the processes they use to make sense and accommodate the illness in their life. Increasing our understanding of these processes is warranted to improve patient care.

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Introduction

Latest worldwide incidence rates for all types of leukaemia are estimated at 350,434 new cases, while there are approximately 257,000 leukaemia-related deaths (Ferlay et al., 2010). Acute leukaemia refers to a group of haematological malignancies characterised by an increase in the number of myeloid cells or lymphocytes in the bone marrow and an arrest in their maturation, resulting in haemopoietic insufficiency with or without leukocytosis (Cornell and Palmer, 2012; Ferrara and Schiffer, 2013; Meenaghan et al., 2012). There are two main types of acute leukaemia: acute lymphoblastic leukaemia (ALL) and acute myeloid leukaemia (AML); these are further classified according to cellular maturity (Cornell and Palmer, 2012; Meenaghan et al., 2012). AML is the most common form of acute leukaemia in adults and its incidence increases with age (Cornell and Palmer, 2012). ALL is the

most common form of leukaemia in childhood, with a secondary increase after the age of 40 years (Cornell and Palmer, 2012; Shaw et al., 2004). The advancements in treatment, molecular profiling and supportive care of leukaemia have increased overall 1-year survival to 64.5% and 5-year survival to 44% of all diagnosed cases (Ferrara and Schiffer, 2013; UK).

As patients with acute leukaemia require prolonged and intensive chemotherapy treatment in the hospital, the impact of their illness on their lives can be profound. Living with leukaemia can challenge their physical, emotional and psychological well-being and functioning (Oliva et al., 2011; Redaelli et al., 2004; Schumacher et al., 1998). Moreover, quality of life has been shown to be mostly affected during the period of active chemotherapy treatment and within the first months after bone marrow transplantation (Hjermstad et al., 1999; Persson et al., 2001; Schumacher et al., 1998, 2002; Tschuschke et al., 2001). At this period, receiving social support has been shown to increase survival (Pinquart et al., 2007).

Understanding patients' experiences of acute leukaemia and the meanings they ascribe to them can help to support patients' coping

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processes (Steeves, 1992; Xuereb and Dunlop, 2003). Synthesising the available evidence deriving from primary qualitative studies has the potential to provide a more in-depth and coherent understanding of patients' experiences (Dixon-Woods and Fitzpatrick, 2001; Flemming, 2010; Sandelowski and Barroso, 2007; Tong et al., 2012) as well as to inform care provision.

The aim of this review was to systematically identify and synthesise qualitative evidence on how adult patients diagnosed with acute leukaemia experience living with their illness. Reporting of this thematic synthesis follows the guidelines for Enhancing Transparency in Reporting the synthesis of Qualitative research (ENTREQ) statement (Tong et al., 2012).

Methods

Research question

The research question of this qualitative thematic synthesis was the following: how do adult patients with acute leukaemia experience their illness?

Synthesis methodology

The method selected for analysing the qualitative material was the thematic synthesis approach by Thomas and Harden (2008). Thematic synthesis is an approach that combines elements from meta-ethnography and grounded theory and allows methodologically heterogeneous studies to be synthesised (Barnett-Page and Thomas, 2009; Thomas and Harden, 2008). It is philosophically underpinned by critical realism according to which the "knowledge of reality is mediated by our perceptions and beliefs" (Barnett-Page and Thomas, 2009). The end synthetic product has the added value of informing policy makers and health care practice.

Search strategy

In order to ascertain that the relevant literature on the chosen topic would be accessed, a sensitive systematic search strategy was developed and run in seven electronic databases: Medline, CINAHL, EMBASE, PsychINFO, BNI & archive, SSCI and ASSIA. The strategy consisted of two strings combining free text terms, thesaurus terms and broad-based terms (Flemming and Briggs, 2007): one for qualitative methods, based on the Rochester qualitative filter adapted by Jones (Jones, 2004) and one for acute leukaemia, created initially for Medline and then adapted for the rest of the databases. The search strategy can be found in the Appendix provided.

Study eligibility criteria

Papers were included in the study if the following criteria applied:

- Studies using qualitative methods to elicit patients' in-depth experiences of acute leukaemia.
- Study samples of adult patients (>18 years of age) diagnosed with acute leukaemia.
- Published in peer reviewed journals.
- Time period: 01/1990–01/2013 (updated from 10/2010–01/2013).
- English language.

Due to time constraints grey literature, conference abstracts and thesis dissertations were excluded from this review.

Screening process

The electronic search was initially conducted in November 2010; however in order to keep the synthesis up-to-date with research being conducted, the search was repeated in 01/02/2013 to identify new studies published until January 2013. Aggregated results from both searches are reported in Fig. 1. The search yielded 15,125 papers. Following the screening process, the final sample consisted of seven original articles reporting six studies conducted exclusively with patients with acute leukaemia (Bertero and Ek, 1993; Farsi et al., 2012; Friis et al., 2003; Koehler et al., 2011; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). The authors decided to also include two additional studies, which also included patients with chronic leukaemia but where at least 75% of the sample were patients with acute leukaemia (Bertero, 1998; Persson and Hallberg, 1995). The reference lists from the ten included studies were then hand-searched. Further searches were conducted across all seven databases using the authors' names from the ten relevant papers as keywords. Additionally, archive, hand searches were performed in three selected journals (*Leukaemia research*, *Psycho-oncology*, *Qualitative Health Research*). Finally, authors from the included studies were contacted by email and asked if they were aware of any other relevant studies or if any relevant papers were in press. None of these additional search strategies yielded new articles.

Appraisal process

As there is no consensus on a list of criteria by which to appraise qualitative evidence, three different methods were employed, to enhance rigour: a guide proposed for reading qualitative articles (Sandelowski and Barroso, 2007), a validated scoring system (Hawker et al., 2002) and a typology for classifying findings (Sandelowski and Barroso, 2007) (Table 1). Appraisal of all selected papers was carried out by CP; a subsample ($n = 3$) of articles was independently appraised by BMJ and MTH. Independent scores were cross-checked for consistency, and any differences were resolved within the team. All papers were considered to be of reasonable methodological quality and included in the final synthesis (Table 1).

Data management

The thematic synthesis was guided by the steps described by Thomas and Harden (2008). The first stage of analysis included free sentence-by-sentence coding of all passages under the heading "findings" or "results". At the end of this process all members of the team ensured that all text corresponded at least to one code and were consistently interpreted. In the second stage one reviewer (CP) looked for similarities and differences between the free codes from the previous stage. In that way the free codes were organised in hierarchical order under a range of descriptive themes. These were subsequently discussed and agreed upon within the team. For these two stages of the synthesis the computer software NVivo®8 was used to facilitate the process. In the final synthesis stage the development of four analytical themes occurred, by further conceptually organising the descriptive themes, in an effort to answer the research question.

Results

Description of the final sample

A summary of the characteristics of the articles reviewed is provided in Table 2. The final sample for this thematic synthesis

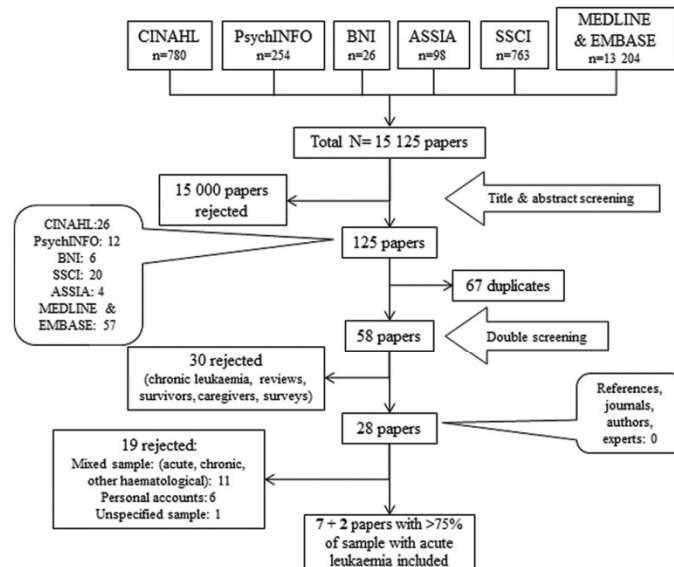


Fig. 1. Flowchart of the article selection process.

consisted of nine original papers reporting on eight studies for a total of 77 patients diagnosed with acute leukaemia. Patient sample sizes varied from 4 to 21 patients; six studies (67%) originated from Europe. The majority of the papers ($n = 6$) were published from 2001 to 2013. More than half of the papers adopted a grounded theory approach (56%). Other methods included hermeneutic phenomenology, content analysis, and ethnography.

Thematic synthesis: a person's path to build a renewed self (Fig. 2)

The literature provided 287 free codes, which were organised in hierarchical order under a range of eleven descriptive themes: initial reactions to diagnosis, life in hospital, losses, interpersonal relationships, emotional impact, coping, hope, support, information, personal values and finding meaning. In the final synthesis stage four analytical themes emerged, namely: the blow of diagnosis; a contracting world; buffers; and accommodating leukaemia (Fig. 2).

Table 1
Quality appraisal for qualitative evidence.

- The reading guide proposed by Sandelowski and Barroso, 2007 comprises of 14 separate domains: research problem, research purpose/questions, literature review, mindset toward the target phenomenon, method, sampling strategy/techniques, sample, data collection techniques/sources, data management techniques, findings, discussion, validity, ethics and overall form.
- Hawker et al. (2002) checklist is a validated scoring system that comprises of ten questions/components each one given a quality score ranging from 4 (good) to 1 (very poor), which generates a maximum score of 40.
- Classification of each study's findings using the typology introduced by Sandelowski and Barroso (2007). The typology is presented in the form of a "continuum of data transformation": i. no findings, ii. topical survey, iii. thematic survey, iv. thematic/conceptual description and v. interpretive explanation.

The blow of diagnosis

The diagnosis of acute leukaemia can shatter a person's life like a blow. The first encounter with the illness ignites a range of reactions, the type or the level of which does not appear to be influenced by gender (Meenaghan and Dowling, 2010). The shock of diagnosis, feelings of disbelief ("it's not happening to me", "it's like a film") and fears of isolation ("the worst part of all is being in the room") were the most prevalent reactions (Friis et al., 2003; Koehler et al., 2011; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). The actual moment of learning the diagnosis was extensively described in the studies focussing on the words that were used by participants and the evoked emotional response such as: a numb sensation, uncertainty and shock (Farsi et al., 2012; Friis et al., 2003; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). Moreover, patients struggle due to the difficulty in attributing a cause to their leukaemia, as usually there had been no sign of them being ill (Bertero, 1998; Koehler et al., 2011; Koenigsmann et al., 2006). The way these patients perceive illness is that minor symptoms are caused by minor illnesses, whereas major symptoms mean serious illnesses (Farsi et al., 2012; Koenigsmann et al., 2006):

"Prior to diagnosis, most participants did not pay any attention to the signs and symptoms of their illness. They chose rather to relate such to prior experiences or other diseases" (Farsi et al., 2012) (p.101).

Even the word "leukaemia" appears to be difficult to grasp. Patients may learn and adopt the terminology of the illness in their vocabulary, without necessarily understanding it (Koenigsmann et al., 2006).

Treatment initiation follows shortly after the announcement of leukaemia (Friis et al., 2003; Koenigsmann et al., 2006). This lack of time and space to prepare has an impact on patients' initial efforts to understand their illness. The quick onset of the treatment is the

Table 2

Summary of characteristics of the 9 articles included in the thematic synthesis.

Study, year; origin	Research design	Theoretical framework, method & analysis	N	Sampling	Demographic characteristics	Context	HC; T
(Farsi et al., 2012); Iran	Exploratory, longitudinal; 3 serial interviews: pretransplant, 2–6 months posttransplant	GT by Corbin & Strauss	10	Convenience	Age range: 18–48 yrs; 6 AML, 4 ALL, 70% married	Specialised BMT centre	35; CD
(Koehler et al., 2011); Germany	Exploratory, cross-sectional	GT & Content analysis; SSI	12	Consecutive	Age range: 21–76 yrs; 6 men, all AML	Haematological ward	27; ThS
(Farsi et al. 2010); Iran	Exploratory, longitudinal; 3 serial interviews: pretransplant, 2–6 months posttransplant	Content analysis	10	Convenience	Age range: 18–48 yrs; 6 AML, 4 ALL, 70% married	Specialised BMT centre	33; TS
(Meenaghan and Dawling, 2010); Ireland	Exploratory, cross-sectional	IPA by Heidegger; SSI, Van Manen's analysis	7	Purposive	Age range: 60–79 yrs; 4 men	Haematological ward	29; ThS
(Koenigsmann et al., 2006); Germany	Exploratory, cross-sectional	GT & Content analysis; SSI	12	Consecutive	Age range: 21–70 yrs; 6 AML, 6 ALL, 5 male	Haematological ward	30; ThS
(Friis et al., 2003); Denmark	Exploratory, longitudinal; 2 serial interviews: after diagnosis, 2–5 months later.	Ethnography, SSI, domain analysis	21	Consecutive	57% > 50 yrs; all AML	University Hospital	35; TD
(Bertero, 1998); Sweden	Exploratory, participant observation	GT, CCA	4	Theoretical	Age range: 31–61 yrs; 3 AML, 1 CML	Haematological ward	36; CD
(Persson and Hallberg, 1995); Sweden	Exploratory, cross-sectional	Ricoeur's hermeneutic phenomenology	5	Consecutive	Age range: 60–77; 4 AL, 1 HML	Haematological ward	28; ThS
(Bertero and Ek, 1993); Sweden	Exploratory, cross-sectional	GT, SSI	8	Theoretical	Age range: 22–73 yrs; 4 AML, 3 ALL, 1 CML	County Hospital	33; CD

Abbreviations: BMT = Bone Marrow Transplant; GT = Grounded Theory; HC = Hawker's Checklist score; T = Typology; ThS = Thematic Survey; CD = Conceptual Description; TD = Thematic Description; TS = Topical Survey; CCA = constant comparative analysis; SSI = Semi-Structured Interviews, IPA = Interpretive Phenomenological Analysis; AML = Acute Myeloid Leukaemia; ALL = Acute Lymphoblastic Leukaemia; CML = Chronic Myeloid Leukaemia; yrs = years.

main factor in facilitating understanding of the seriousness of their condition (Farsi et al., 2012; Koehler et al., 2011; Koenigsmann et al., 2006).

A contracting world

In confronting the new reality patients find themselves living in a contracting world. They move from being people moving in their own social context to being hospitalised patients, and finally, patients with leukaemia (Bertero, 1998). In a short period of time, their world has shrunk to the confines of their hospital bed, a transition symbolised further by the change in their clothing (Bertero, 1998; Farsi et al., 2012; Meenaghan and Dowling, 2010; Persson and Hallberg, 1995).

Moreover, patients with acute leukaemia have to spend a significant amount of time in hospital to receive intensive chemotherapy. Life in hospital is dominated by diagnostic procedures and treatment decisions, i.e. rates regarding prognosis and effectiveness of the treatment (Bertero, 1998; Friis et al., 2003; Koenigsmann et al., 2006). Among the most prevalent procedures is bone marrow biopsy, often seen by patients as a violation of their integrity and a reminder of the threat of leukaemia (Koenigsmann et al., 2006). Dealing with the side effects of treatment, such as fever and fatigue, is another part of the of hospital life (Bertero, 1998; Farsi et al., 2010; Farsi et al., 2012; Koenigsmann et al., 2006; Persson and Hallberg, 1995). Interestingly, patients did not always understand the seriousness and relevance of these symptoms to their overall health status (Koenigsmann et al., 2006; Persson and Hallberg, 1995).

The emotional impact of acute leukaemia becomes more evident at this stage. The diagnosis of leukaemia leaves no space for reflection; it is at this point that patients start to feel threatened and in certain cases helpless (Koenigsmann et al., 2006; Persson and Hallberg, 1995). They live in a world of uncertainty, doubts and fear of death (Bertero, 1998; Farsi et al., 2010; Farsi et al., 2012; Meenaghan and Dowling, 2010).

Due to the myelosuppressive treatment, patients are facing deliberate social isolation (Bertero, 1998; Farsi et al., 2010; Farsi et al., 2012; Meenaghan and Dowling, 2010; Persson and Hallberg, 1995). While they comprehend the reasons for the physical

confinement, they fear further alienation from their social world (Bertero, 1998; Meenaghan and Dowling, 2010). On several occasions, nurses' negative attitude when performing tasks without actually spending quality time with them further increased their sense of isolation (Bertero, 1998).

In their isolation rooms, patients also begin to realise their losses: the loss of personal control, loss of independence, loss of normality and the loss of their future. Everything is decided on their behalf and they are encouraged to follow clinicians' suggestions (Koehler et al., 2011; Persson and Hallberg, 1995). Their daily routine is replaced by the hospital routine and then disrupted by the long-term effects of the treatment (Farsi et al., 2012; Koenigsmann et al., 2006). Consequently, they see leukaemia as a threat to their ability for future planning and eventually as a threat to their life (Koenigsmann et al., 2006; Persson and Hallberg, 1995).

The interpersonal relationships of patients with leukaemia can be illustrated as being organised in three circles; the first circle includes their family, the second includes their friends and the third level comprises of the health care professionals (Bertero and Ek, 1993; Bertero, 1998; Meenaghan and Dowling, 2010). Families, comprising the closest circle, face the greatest strain; friends are vital for socialising, while health care professionals may be patients' link with the outside world (Bertero, 1998). In all, the importance of interpersonal relationships was emphasised as "an important source of strength which enables them to continue struggling, to go on living" (Bertero and Ek, 1993) (p.1349).

Buffers

As patients' world contracts, there are a number of factors serving as buffers, potentially absorbing the strains posed by acute leukaemia. The presence of support, information, coping, and hope, impacts on how patients make sense of their experience.

Support

The importance of being supported in their new reality, either by health care professionals or their loved ones, was expressed in a number of accounts (Bertero and Ek, 1993; Friis et al., 2003; Meenaghan and Dowling, 2010). Patients recognise being

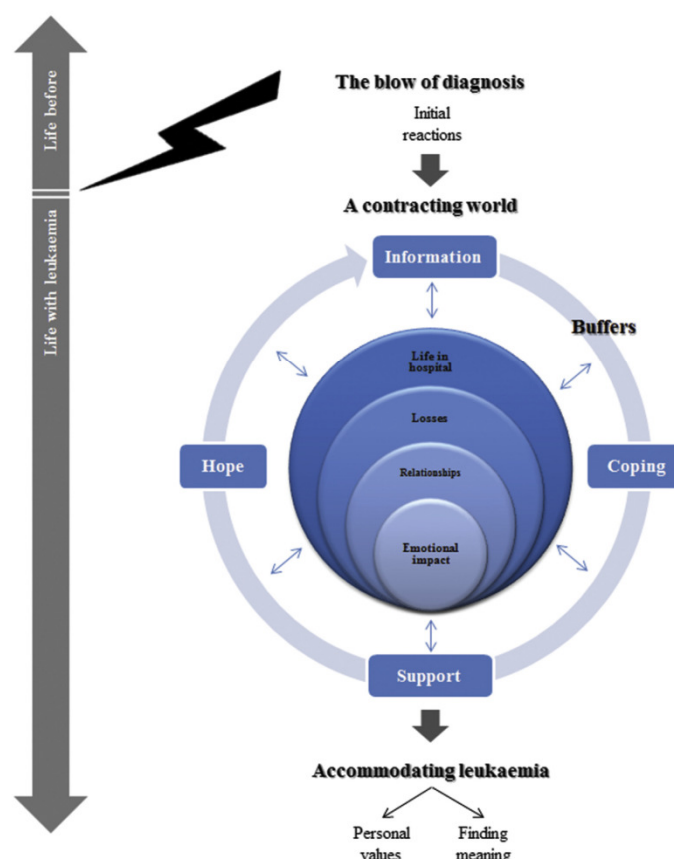


Fig. 2. Experiencing Leukaemia: A person's path to build a renewed self.

respected as individuals and conversing with others as basic elements of support. Having faith and trust in clinicians and being respected in turn were important aspects of feeling supported and increased their sense of security (Bertero and Ek, 1993; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). Specifically, patients' sense of security was affected by waiting and visiting times as well as by communication with others (Bertero and Ek, 1993; Meenaghan and Dowling, 2010). Conversely, lack of trust in health care professionals, not being respected as individuals by being put back in their "patient-suits" were conceived as hindering support (Bertero and Ek, 1993; Bertero, 1998; Koenigsmann et al., 2006). Furthermore, patients with acute leukaemia explained how support increased their level of autonomy. Autonomy was seen as an aspect of positive attitude with performance ability, self-esteem and dignity being its major components (Bertero and Ek, 1993; Koehler et al., 2011; Persson and Hallberg, 1995). Even being able to manage seemingly trivial matters, like taking their temperature, increased their feelings of independence (Bertero and Ek, 1993).

Information

The type, time and impact of information provided to patients with leukaemia was another buffer. Patients with leukaemia were

happy with the information they received (Friis et al., 2003; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). Acknowledging the fact that not all patients want to be informed, accurate information to both patients and families was highly valued (Bertero and Ek, 1993; Bertero, 1998; Farsi et al., 2010; Friis et al., 2003; Koehler et al., 2011; Koenigsmann et al., 2006). From this set of studies, it was unclear whether information needs actually change over time (Friis et al., 2003). Albeit, the impact of information was strongly stressed as a key element in quality of life (QoL), in maintaining hope, reinforcing control and autonomy, facilitating acceptance and adaptation and increasing trust in clinicians (Bertero and Ek, 1993; Farsi et al., 2010; Friis et al., 2003; Koehler et al., 2011; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010; Persson and Hallberg, 1995).

Coping

In the studies under review, coping as a process was explored and a number of helpful and unhelpful coping strategies were reported. Factors that serve as barriers or facilitators for coping were also identified (Farsi et al., 2012). Taking action, which involves adaptation and acceptance, as well as consciously adopting a positive attitude were the most common positive coping styles

(Bertero, 1998; Farsi et al., 2010; Farsi et al., 2012; Meenaghan and Dowling, 2010). Adopting a fighting spirit and taking charge of all possible resources; working through the difficulties; relying on faith and acknowledging their personal influence were also stressed (Farsi et al., 2010; Farsi et al., 2012; Koehler et al., 2011; Koenigsmann et al., 2006). Patients with leukaemia may also use unhelpful coping styles, such as denial and avoidance, they can choose to keep a distance from the situation or even adopt a more fatalistic attitude (Bertero, 1998; Farsi et al., 2010; Farsi et al., 2012; Koehler et al., 2011; Persson and Hallberg, 1995). Of interest is the fact that on several occasions, patients with acute leukaemia used contradicting coping styles (Farsi et al., 2012; Koenigsmann et al., 2006; Persson and Hallberg, 1995).

Hope

Finally, patients perceived that hope helped them cope with their leukaemia (Farsi et al., 2010; Farsi et al., 2012; Friis et al., 2003; Koenigsmann et al., 2006). In fact, hope changed over time, with patients reporting increased hopes as their treatment progressed (Farsi et al., 2012). In all, patients' hopes were focused on being able to control their leukaemia and thus have hope for the future (Farsi et al., 2012; Friis et al., 2003; Koenigsmann et al., 2006).

Accommodating leukaemia

In order to build a renewed self, patients make sense of their experience through reprioritising their personal values and finding new meaning. The joy of being alive and in fact having a positive attitude to life in general was vital for patients (Bertero and Ek, 1993). Life satisfaction together with living for today, here and now, were values of paramount importance (Farsi et al., 2010; Koenigsmann et al., 2006). Accordingly, leukaemia changed the perception of what accounts for a good QoL (Bertero and Ek, 1993). Patients reported finding happiness in small, trivial things and taking nothing for granted (Bertero and Ek, 1993; Farsi et al., 2012). Key elements that mediate QoL are the coping strategies patients implement, and information and support received from their clinicians (Bertero and Ek, 1993). This process indicated the beginning of reprioritising personal values (Bertero and Ek, 1993; Farsi et al., 2012; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010).

In the reviewed studies, it was apparent that having leukaemia leads patients to re-evaluate their lives (Bertero and Ek, 1993; Farsi et al., 2010; Farsi et al., 2012). Often patients questioned the meaning in life, and the meaning of life (Bertero and Ek, 1993; Koenigsmann et al., 2006). Their ability to socialise was an important resource for them; reflection and being mindful enabled them to live their lives in full. As new meanings are created, patients' perceptions of themselves and of others may play an important role. They confront the issue of mortality by accepting the possibility of death (Bertero and Ek, 1993; Farsi et al., 2012; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). It is only then that they can experience closure and move on with their life (Farsi et al., 2012).

Discussion

This qualitative thematic synthesis provides a first systematic overview of the experience of acute leukaemia in adult patients. The proposed conceptual model explains the path that patients follow in order to build a renewed self: dealing with the blow of diagnosis, living in a contracting world and accommodating their illness in their lives.

The synthesis results are indicative of the impact acute leukaemia has on patients' lives. Acute leukaemia is often a perceived watershed moment in their lives separating life *before*

from life *with* the illness. The time following diagnosis along with the treatment period is very challenging for patients. Moreover, as a number of patients require specialised treatments (i.e. bone marrow or stem cell transplantation), patients and their families may have to relocate to distant capital centres that can also increase their anxiety (McGrath, 1999a,b; McGrath and Holeywa, 2012; Schulz-Kindermann et al., 2002). Indeed, in a review of all quantitative studies on the effects of acute myeloid leukaemia on reported QoL concluded that this is the time when the negative burden is most evident (Redaelli et al., 2004).

After the initial shock of the diagnosis subsides, patients with acute leukaemia have to deal with their contracting world. Their lives are dominated by the new hospital routine. Unlike other patients with cancer, their diagnosis of acute leukaemia dictates prolonged hospitalisation (Meenaghan et al., 2012). They realise the various losses that their illness has brought in their lives. Experiencing cancer through loss has been reported in the literature (Deimling et al., 2002; Fillip, 1992; Wicks and Mitchell, 2010). In this synthesis the emotional impact of acute leukaemia was also evident. Dealing with feelings of uncertainty and the fear of dying were the most common emotional responses reported. Indeed in a study conducted in patients with acute and chronic leukaemia illness was perceived both as a threat to one's ability for future planning and a threat to their life (Ersek, 1992). Living in their shrinking world, patients with acute leukaemia mentioned the importance of interpersonal relationships. They provided them a source of strength and a sense of security.

A recent review of the literature on the coping strategies of patients' with haematological malignancies has indicated that patients' subjective theories of illness can determine their coping strategies (Koehler et al., 2009). The most common coping strategies according to this review are gaining control and raising hope. This finding is in agreement with the conceptual model from this meta-synthesis. Authors support the idea that an "essential coherence" exists between subjective illness theories and individual coping strategies (Koehler et al., 2009). In the model that evolved from this synthesis, patients use previous frames of reference in order to make sense of their experience, and quite often, they use contradicting coping strategies concurrently. In the context of bone marrow transplantation, patients with leukaemia identified emotional support, acceptance and taking control as the most common coping strategies they employ (Grulke et al., 2005). This synthesis explained why patients with leukaemia chose these specific strategies: they try to regain to some extent their old normality. Another coping strategy identified in this model was religious coping. Relying on faith has been reported in the context of bone marrow transplantation previously (Coolbrandt and Gryphonck, 2010; Saleh and Brockopp, 2001). Steeves, in a preliminary study, suggested that for patients undergoing bone marrow transplantation with a previously stated religious affiliation, faith in God was crucial in their meaning making process (Steeves, 1992). On the other hand, the presence of coping strategies such as distraction and fighting spirit, as well as improved QoL in elderly patients with leukaemia, seem to be related with increased survival rates (Oliva et al., 2011; Tschuschke et al., 2001). The development of interventions aiming to enhancing patients' coping strategies has the potential to increase their survival, which is the ultimate goal of treatment.

Social support has been identified as a buffer to the psychological impact of cancer previously (Kornblith et al., 2001). In haematological oncology most of the health related outcome measures that have been used predominantly assess physical symptoms and social functioning (Xuereb and Dunlop, 2003). Furthermore, researchers have investigated the factors affecting patients' survival rates. Evidence supports the idea that social

support, and rather practical support, at the beginning of the treatment enhances survival (Pinquart et al., 2007). In a comparison of daily life problems during treatment in patients with acute leukaemia and patients with malignant lymphoma patients with leukaemia reported lower satisfaction with the practical help provided (Persson et al., 1997). Results from this thematic synthesis indicate that patients' families are their primary sources of support during the treatment (Bertero and Ek, 1993; Bertero, 1998; Meenaghan and Dowling, 2010). However, there is limited evidence regarding the caregiving experience of patients with acute leukaemia (Persson et al., 1998; Tamayo et al.). Future studies should include exploring the experience of family members of patients with leukaemia in order to gain a deeper understanding of the experience from their perspective.

Existing literature on patients with leukaemia has also focused on patients' information needs (Mohamedali et al., 2010; Yogaparan et al., 2009). More specifically, patients are happy with the information they are being provided and prefer a passive collaboration decision-making role, while the majority do not know their prognosis (Mohamedali et al., 2010; Yogaparan et al., 2009). Patients in the reviewed studies appear to corroborate this claim. All study participants agreed that information was of significant importance, and in most studies they were happy with the information they received from their clinicians (Farsi et al., 2010; Friis et al., 2003; Koenigsmann et al., 2006; Meenaghan and Dowling, 2010). The majority of these patients are receiving treatment regimens as part of clinical trials. Thus, in the process of consenting for their treatment, they do receive written as well as verbal information. Despite the fact that patients with leukaemia think that they are well-informed, they do not always understand the information provided (Persson and Hallberg, 1995). It remains unclear whether patients' information needs change over the course of treatment (Friis et al., 2003).

Results from this thematic synthesis suggest that hope played a buffering role as it facilitated patients' coping process. In an early study in patients with acute and chronic leukaemia maintaining hope was seen as a dual action process: dealing with leukaemia and at the same time keeping it in its place (Ersek, 1992). This means that patients try to face and cope with their illness and at the same time preserve a sense of normality in their life.

Finally, current body of evidence suggests that accommodating acute leukaemia through reprioritising values and finding meaning is an integral part of patients' making sense process. The meaning of leukaemia in the context of bone marrow transplantation has been investigated previously (Steeves, 1992; Xuereb and Dunlop, 2003). In a similar context, patients undergo a process of reprioritising and adopt a changed outlook in life (Stephens, 2005).

Limitations of literature and future research

Acute leukaemia is not a common cancer in adults, the majority of published evidence, therefore, originated from mixed samples of patients with chronic leukaemia and other types of malignancies. It was usually not possible to extricate findings specific to patients with acute leukaemia; this explains the small sample size of original studies included in the synthesis.

The conceptual model described for patients with leukaemia also has potential limitations. Arguably, these limitations derive from the limitations of the original studies that were included in this thematic synthesis. According to Sandelowski's typology only four out of the nine included studies were classified as "conceptual" as or "thematic" descriptions, while no study classified "interpretive explanation". Despite the fact that appraising qualitative work is a subjective task, the synthesis' findings may be compromised by the level of initial interpretation by the authors in the original

studies. The proposed model should be made more explicit in further qualitative studies, as it is directly influenced by how data is analysed.

Context, either referring to culture or to setting, is an important element in qualitative research (Sandelowski and Barroso, 2007). The majority of this synthesis' sample consisted of studies conducted in Europe. The diversity of health care systems has to be acknowledged when considering the level of patient information and support over the course of their leukaemia trajectory. Patients from different cultural backgrounds may have different needs and coping styles. In this synthesis, the study conducted in Iran reported religious coping as an important strategy the patients used to deal with their acute leukaemia (Farsi et al., 2010; Farsi et al., 2012). Future research in the field in more culturally diverse populations is warranted to provide further insights. Furthermore, due to dearth of research in this population, the studies included in the synthesis were conducted in variety of clinical settings. Patients with acute leukaemia in their first stages of their treatment have different needs from those undergoing bone marrow transplantation; therefore research targeting specific time points in the cancer journey is needed.

Clinical implications

The synthesis highlights the need for clinicians to be aware that patients' quality of life is most affected starting with the period after diagnosis until the end of their treatment. Psychosocial interventions targeted at this period would be most beneficial for patients with leukaemia. Helping patients identify their old frames of reference enhances their ability to make sense of acute leukaemia. Preserving patients' autonomy and including them in the decision-making process is important even in the face of trivial tasks as it makes a difference to their perception of control during their hospital life. Providing information that is easy to understand is paramount; the use of visual aids has proven to be useful. Finally, supporting families as well as patients is important as it has been shown that they are the main sources of support during the patients' illness.

Limitations of the current synthesis

This thematic synthesis has limitations that warrant commenting. The search strategy was purposefully sensitive, thus aiming at including all relevant literature. However, it was not exhaustive but limited to peer-reviewed articles and reports published in the English language only. Additionally, due to time constraints the grey literature was not searched. Accessing qualitative studies can be challenging due to lack of a standardised classification in electronic databases (Shaw et al., 2004). Therefore, it is necessary to acknowledge the possibility that relevant original studies might have been missed in this review; however it is believed that this has been kept to a minimum.

Conclusions

This review provides a thematic synthesis of all empirical findings on patients with acute leukaemia. Making sense of the experience of leukaemia helps patients accommodate to life with the illness and adapt their outlook. In conducting this synthesis, the dearth of qualitative evidence in this specific group of patients was evident. Further studies are needed, particularly with a focus on patients with acute leukaemia from different cultural backgrounds. Moreover, including their families will assist the development of key interventions for people affected by this illness.

Statement of conflicts of interest

The authors declare that there are no personal or financial conflicts of interest with regard to this work.

Appendix

Search strategy for MEDLINE & EMBASE

1. ((attitude/ or cluster sampl\$.mp. or constant comparative method.mp. or content analysis.mp. or discourse analysis.mp. or ethnographic research.mp. or ethnological research.mp. or ethnonursing research.mp. or exp patients attitudes/) and perceptions/) or exp Attitude/ or exp Research Methods/ or field stud\$.mp. or focus group\$.mp. or Focus Groups/ or life experience\$.mp. or nursing methodology research.mp. or Nursing Methodology Research/ or observational method\$.mp. or phenomenological research.mp. or phenomenology.mp. or interpretation/ or purposive sample.mp. or Qualitative Research/ or qualitative stud\$.mp. or qualitative validity.mp. or questionnaire/ or Questionnaires/ or theoretical sampl\$.mp.
2. ethnonursing.af. or ethnograph\$.mp. or phenomenol\$.af. or life stor\$.mp. or women\$ stor\$.mp. or (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$.af. or participant observ\$.tw. or (social construct\$ or postmodern\$ or post-structural\$ or poststructural\$ or poststructural\$ or postmodern\$ or post-modern\$ or feminis\$ or interpret\$.mp. or (action research or cooperative inquir\$ or co-operative inquir\$ or co-operative inquir\$.mp. or (humanistic or existential or experiential or paradigm\$.mp. or (field stud\$ or field research).tw. or human science.tw. or biographical method.tw. or qualitative validity.af. or theoretical sampl\$.af. or focus group\$.af. or (account or accounts or unstructured or open-ended or open ended or text\$ or narrative\$.mp. or life-world.mp. or life world.mp. or conversation analys\$.mp. or personal experience\$.mp. or theoretical saturation.mp. or lived experience\$.tw. or life experience\$.mp. or cluster sampl\$.mp. or theme\$.mp. or thematic.mp. or categor\$.mp. or observational method\$.af. or questionnaire\$.mp. or content analysis.af. or thematic analysis.af. or constant compare\$.af. or narrative analysis\$.af. or heidegger\$.tw. or colaizzi\$.tw. or speigelsberg\$.tw. or manen\$.tw. or kaam\$.tw. or merleau ponty\$.tw. or husserl\$.tw. or giorgi\$.tw. or foucault\$.tw. or glaser\$.tw.
3. (purpos\$ adj4 sampl\$.af. or (strauss\$ adj2 corbin\$.tw. or (grounded adj (theor\$ or study or studies or research or analys\$ s)).af. or (data adj1 saturat\$.tw.
4. 1 or 2 or 3.
5. leukemia.mp.
6. exp Leukemia, Lymphoid/ or exp Leukemia, Myeloid, Acute/ or exp Leukemia/ or Leukaemia.mp.
7. 5 or 6.
8. 4 and 7.

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Appendix 2. Search Strategies

Search strategy for MEDLINE & EMBASE

1. ((attitude/ or cluster sampl\$.mp. or constant comparative method.mp. or content analysis.mp. or discourse analysis.mp. or ethnographic research.mp. or ethnological research.mp. or ethnonursing research.mp. or exp patients attitudes/) and perceptions/) or exp Attitude/ or exp Research Methods/ or field stud\$.mp. or focus group\$.mp. or Focus Groups/ or life experience\$.mp. or nursing methodology research.mp. or Nursing Methodology Research/ or observational method\$.mp. or phenomenological research.mp. or phenomenology.mp. or phenomenology/ or purposive sample.mp. or Qualitative Research/ or qualitative stud\$.mp. or qualitative validity.mp. or questionnaire/ or Questionnaires/ or theoretical sampl\$.mp.
2. ethnonursing.af. or ethnograph\$.mp. or phenomenol\$.af. or life stor\$.mp. or women\$ stor\$.mp. or (emic or etic or hermeneutic\$ or heuristic\$ or semiotic\$).af. or participant observ\$.tw. or (social construct\$ or postmodern\$ or post-structural\$ or post structural\$ or poststructural\$ or post modern\$ or post-modern\$ or feminis\$ or interpret\$).mp. or (action research or cooperative inquir\$ or co operative inquir\$ or co-operative inquir\$).mp. or (humanistic or existential or experiential or paradigm\$).mp. or (field stud\$ or field research).tw. or human science.tw. or biographical method.tw. or qualitative validity.af. or theoretical sampl\$.af. or focus group\$.af. or (account or accounts or unstructured or open-ended or open ended or text\$ or narrative\$).mp. or life-world.mp. or life world.mp. or conversation analys?s.mp. or personal experience\$.mp. or theoretical saturation.mp. or lived experience\$.tw. or life experience\$.mp. or cluster sampl\$.mp. or theme\$.mp. or thematic.mp. or categor\$.mp. or observational method\$.af. or questionnaire\$.mp. or content analysis.af. or thematic analysis.af. or constant compare\$.af. or narrative analys?s.af. or heidegger\$.tw. or colaizzi\$.tw. or speigelberg\$.tw. or manen\$.tw. or kaam\$.tw. or merleau ponty\$.tw. or husserl\$.tw. or giorgi\$.tw. or foucault\$.tw. or glaser\$.tw.
3. (purpos\$ adj4 sampl\$).af. or (strauss\$ adj2 corbin\$).tw. or (grounded adj (theor\$ or study or studies or research or analys?s)).af. or (data adj1 saturat\$).tw.
4. 1 or 2 or 3
5. leukemia.mp.
6. exp Leukemia, Lymphoid/ or exp Leukemia, Myeloid, Acute/ or exp Leukemia/ or Leukaemia.mp.
7. 5 or 6
8. 4 and 7
9. limit 8 to (english language and yr="1990 -01/2013")
10. limit 9 to yr="1990 - 2000"
11. limit 9 to yr="2001 - 2005"
12. limit 9 to yr="2006 -01/2013"
13. remove duplicates from 10

14. remove duplicates from 11
15. remove duplicates from 12
16. 13 or 14 or 15

Search strategy for meaning in the context of cancer – patient perspective

1. cancer.mp. or exp Neoplasms/
2. (meaning or meaning-making or "search for meaning" or "finding meaning" or existential or "sense of coherence" or self-transcendence or "appraisal coping").mp.
3. 1 and 2
4. limit 3 to (english language and yr="2004 -05/2012")
5. remove duplicates from 4

Search strategy for meaning in the context of cancer – caregiver perspective

1. cancer.mp. or exp Neoplasms/
2. (meaning or meaning-making or "search for meaning" or "finding meaning" or existential or "sense of coherence" or self-transcendence or "appraisal coping").mp.
3. caregiver\$.mp. or carer\$.mp. or caregiving.mp. or partner\$.mp. or family member\$.mp. or significant other\$.mp. or friend\$.mp. or exp Caregivers/
4. 1 and 2 and 3
5. limit 4 to (english language and yr="1997 -05/2012")
6. remove duplicates from 4

Appendix 3. Quality Appraisal Tools

Reading Guide by Sandelowski and Barroso [79]

<u>Category</u>	<u>Appraisal parameters</u>	<u>Presence</u> <u>(Yes/ No)</u>	<u>Relevance</u> <u>(Yes/ No)</u> Judge as a category
Problem	<ol style="list-style-type: none"> 1. There is a discernible problem that led to the study. 2. The problem is accurately depicted. 3. The problem is related to the research purpose and/or the literature review. 4. The problem establishes the significance of the research purpose, or why the researcher wanted to conduct the study, beyond simply stating that "no one has studied this (qualitatively) before." 	1: 2: 3: 4:	
Purpose(s)/ question	<ol style="list-style-type: none"> 1. There is a discernible set of research purposes and/or questions. 2. Research purposes or questions are linked to the problem and/or to the review of the literature. 3. Research questions are amenable to qualitative study. 	1: 2: 3:	
Literature Review	<ol style="list-style-type: none"> 1. Key studies and other relevant literatures addressing the research problem are included. 2. The review is related to the research problem. 3. The review clarifies whether it reflects what researchers know and believed going into the field of study — before any data were collected — or came to know and believe while in the field coming out of it, after data analysis began or was completed. 4. The review shows a critical attitude, as opposed to simply and/or indiscriminately summarizing studies. 5. The review shows a discernible logic that points toward the research purpose. 	1: 2: 3: 4: 5:	
Mindset toward target phenomenon	<ol style="list-style-type: none"> 1. There is an explicitly stated or implied frame of reference. 2. If explicitly stated, the frame of reference is accurately rendered. 3. Whether stated or implied, the frame of reference fits the target phenomenon. That is, it is not forced onto the target phenomenon. 4. If explicitly stated as the guiding frame of reference for a study, it played a discernible role in the way the study was conducted 	1: 2: 3: 4: 5:	

<u>Category</u>	<u>Appraisal parameters</u>	<u>Presence (Yes/ No)</u>	<u>Relevance (Yes/ No)</u> Judge as a category
	and/or the way the findings were treated. 5. The presentation of the mindset for the study clarifies whether it influenced researchers going into the field of study — before any data were collected — or while in the field or coming out of it, after data analysis began or was completed.		
Method	1. There is a stated or implied method. 2. The method fits the research purpose. 3. The method is accurately rendered. 4. The uses of method-linked techniques for other than method-linked purposes are explained as when theoretical sampling is used in a qualitative descriptive study, or phenomenological techniques are used to create items for an instruments.	1: 2: 3: 4:	
Sampling strategy & techniques	1. The sampling plan fits the purpose and method. 2. The sampling plan is purposeful. 3. The sampling plan described is accurately rendered, as opposed to being inaccurately rendered or misrepresented as when maximum variation sampling is presented as having equal numbers of men and women, or percents of African Americans or Hispanic Americans equal to their presence in the population. 4. Sites of recruitment fit the purpose and sampling strategy.	1: 2: 3: 4:	
Sample	1. Sample size and configuration fit the purpose and sampling strategy. 2. Sample size and configuration can support claims to informational redundancy, or theoretical or scene saturation. 3. Sample size and configuration can support claims to intensive, comprehensive, or holistic studies in particular. 4. Sample size and configuration can support the findings. 5. The sample is presented in a case-oriented way, as opposed to a variable-oriented way. 6. Features of the sample critical to the understading of findings are described, as opposed to not described. 7. Sites of recruitment fit the evolving needs of the study.	1: 2: 3: 4: 5: 6: 7:	
Data collection techniques & sources	1. Data collection techniques and sources fit the purpose and mindsets of the study, as opposed to not fitting them. 2. Specific data collection techniques are tailored to the reported study, as opposed to the presentation of textbook or rote	1: 2: 3: 4: 5: 6:	

<u>Category</u>	<u>Appraisal parameters</u>	<u>Presence (Yes/ No)</u>	<u>Relevance (Yes/ No)</u> Judge as a category
	<p>descriptions of data collection with no application shown to the study reported.</p> <p>3. Data collection techniques are accurately rendered, as opposed to inaccurately rendered as when the observation process that occurs during interviews and focus groups is presented as participant observation.</p> <p>4. The sources of data presented are demonstrably the basis of the findings, as opposed to not being their basis as when document study is presented as a data collection strategy, but there is no evidence of its use.</p> <p>5. Data collection techniques are correctly used, as opposed to misused as when focus groups are conducted by asking each participant in turn to answer the same question, instead of posing a question to the group to stimulate group interaction.</p> <p>6. The sequence and timing of data collection strategies vis-à-vis each other fit the purpose and mindsets of the study.</p> <p>7. Sites are conducive to data collection.</p> <p>8. Alterations in techniques fit the evolving needs of the study.</p> <p>9. The time period for data collection is explicitly stated.</p>	<p>7:</p> <p>8:</p> <p>9:</p>	
Data management techniques	<p>1. Data management techniques fit the purposes and data.</p> <p>2. Specific data management techniques are tailored to the reported study, as opposed to textbook or rote descriptions of data management being offered, with no application shown to the study reported.</p> <p>3. Data management techniques are accurately rendered.</p> <p>4. Data management techniques are correctly used.</p> <p>5. There is a clear plan for analytically linking interview, observation, document, and/or artifact data sets.</p>	<p>1:</p> <p>2:</p> <p>3:</p> <p>4:</p> <p>5:</p>	
Findings	<p>1. There is a discernable set of results distinguishable from the data researchers collected, as opposed to indistinguishable as when the researcher presents several case histories but offers no interpretation of them. This is an example of descriptive excess or heaped description, as opposed to thick description.</p> <p>2. The results of the study are distinguishable from the researcher's discussion of the results</p>	<p>1:</p> <p>2:</p> <p>3:</p> <p>4:</p> <p>5:</p> <p>6:</p> <p>7:</p> <p>8:</p> <p>9:</p> <p>10:</p>	

<u>Category</u>	<u>Appraisal parameters</u>	<u>Presence (Yes/ No)</u>	<u>Relevance (Yes/ No)</u> Judge as a category
	<p>or from the results of other studies to which the researcher refers.</p> <ol style="list-style-type: none"> 3. Interpretations of data are demonstrably plausible and/or sufficiently substantiated with data, as opposed to implausible. 4. Data are sufficiently analyzed and interpreted. 5. Findings address the research purpose, as opposed to not addressing them. 6. Variations in sample and/or data are addressed. 7. Analysis is largely case-oriented, or oriented to the study of particulars, as opposed to variable-oriented or quantitatively-informed. 8. Concepts or ideas are well-developed and linked to each other. 9. Concepts are used precisely, as opposed to imprecisely. 10. Analysis of data fits the data, as opposed to not fitting as when focus group data are analyzed at the individual level and the analysis takes no account of group interaction. 11. The results offer new information about, insight into, or formulation of the target phenomenon. 12. The findings are relevant for contemporary use, as opposed to being irrelevant. 	<p>11: 12:</p>	
Discussion	<ol style="list-style-type: none"> 1. Discussion of findings is based on the study findings previously described, as opposed to being contrary to the findings, or to introducing findings not previously described. 2. The study findings are linked to findings in other studies, or to other relevant literatures either previously discussed or newly introduced. 3. The clinical, policy, theoretical, disciplinary, and/or other significance of the findings is thoughtfully considered, as opposed to indiscriminately considered as when changes in practice are recommended that merely propose actions opposite to the findings (e.g., providers are found to be insensitive so the implication is that they must be educated to become sensitive), or when repeating a study with other populations and/or in other settings is recommended with no rationale. 	<p>1: 2: 3:</p>	
Validity	<ol style="list-style-type: none"> 1. Researchers show an awareness of their influence on the study and its participants. 2. The distinctive limitations of the study are summarized: e.g., theoretical sampling could not be fully conducted in a grounded theory 	<p>1: 2: 3: 4: 5:</p>	

<u>Category</u>	<u>Appraisal parameters</u>	<u>Presence (Yes/ No)</u>	<u>Relevance (Yes/ No)</u> Judge as a category
	<p>study. This is in contrast to summarizing and/or apologizing for the so-called limitations of qualitative research.</p> <ol style="list-style-type: none"> Techniques for validation are used that fit the purpose, method, sample, data, and findings, as opposed to using techniques that do not fit as when reliability coding to ascertain consistency in interview data is used in a study emphasizing the revisionist nature of narratives. Techniques used are tailored to the reported study, as opposed to presentations of textbook or rote descriptions of validation techniques with no application shown to the study reported. Techniques for validation are accurately rendered, as opposed to misrepresented as when descriptive validity is confused with interpretive validity, and triangulation for convergent validity is confused with using different data sources for completeness. Techniques for validation are correctly used, as opposed to incorrectly used as when cases are kept in or dropped from consideration because they conform or do not conform to other cases. 	6:	
Ethics	<ol style="list-style-type: none"> Benefits and risks distinctive to the study are addressed, as opposed to textbook or rote descriptions of human subjects issues being offered with no description of their particular relevance to the reported study. Recruitment and consent techniques were tailored to fit the sensitivity of the subject matter and/or vulnerability of subjects. Data collection and management techniques were tailored to fit the sensitivity of the subject matter and/or vulnerability of subjects. Examples of data provided as evidence to support findings have analytical value and present subjects fairly, as opposed to having only sensational value or presenting subjects unfairly, as when extreme incidents of events are presented when others would do or when quotes are edited that emphasize the lack of education of subjects. 	1: 2: 3: 4:	
Overall Form	<ol style="list-style-type: none"> The overall literary style of the study fits its purpose, method, and findings. Given the reporting style, elements of the research report are placed where readers are likely to find them. There is a coherent logic to the presentation 	1: 2: 3: 4: 5: 6:	

<u>Category</u>	<u>Appraisal parameters</u>	<u>Presence (Yes/ No)</u>	<u>Relevance (Yes/ No)</u> Judge as a category
	<p>of findings.</p> <p>4. Data were organized in ways that do analytic justice to them, as opposed to not doing them justice.</p> <p>5. Visual displays, quotes, cases, and numbers clarify, summarize, substantiate, or otherwise illuminate findings, as opposed to being at odds with them as when a quote has more ideas in it than featured by the researcher or a path diagram shows a relationship between variables at odds with the relationship between them depicted in the text.</p> <p>6. The numerical meaning of such terms as "most", "some", "sometimes", and "commonly" is clear.</p> <p>7. The empirical referent for a theme or concept is clear, as opposed to theme being conflated with experience as when a researcher states that five themes emerged from the data instead of stating that women managed their symptoms in one of five ways; or the writer does not clarify whether the themes s/he is discussing are strategies to accomplish a goal, outcomes of having engaged in these strategies, typologies of behavior, or milestones and turning points in a transition.</p> <p>8. Themes or concepts are presented in a comparative and parallel fashion, as opposed to an unparallel manner as when, in a typology, some types are presented as behaviors, while others are presented as character traits, and each type is not compared to every other type.</p> <p>9. Titles of paper and section headers reflect the content in the paper and sections.</p> <p>10. The form fits the audience for whom the report was produced.</p>	<p>7:</p> <p>8:</p> <p>9:</p> <p>10:</p>	

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Typology of qualitative findings (Please circle)				
No finding	Topical Survey	Thematic survey	Conceptual/ Thematic description	Interpretive explanation
Comments:				

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Hawker et al. [80] Checklist

1. Abstract and title: Did they provide a clear description of the study?

4	Good	Structured abstract with full information and clear title.
3	Fair	Abstract with most of the information.
2	Poor	Inadequate abstract.
1	Very Poor	No abstract.

2. Introduction and aims: Was there a good background and clear statement of the aims of the research?

4	Good	Full but concise background to discussion/study containing up-to-date literature review and highlighting gaps in knowledge. Clear statement of aim AND objectives including research questions.
3	Fair	Some background and literature review. Research questions outlined.
2	Poor	Some background but no aim/objectives/questions, OR Aims/objectives but inadequate background
1	Very Poor	No mention of aims/objectives. No background or literature review.

3. Method and data: Is the method appropriate and clearly explained?

4	Good	Method is appropriate and described clearly (e.g., questionnaires included). Clear details of the data collection and recording.
3	Fair	Method appropriate, description could be better. Data described.
2	Poor	Questionable whether method is appropriate. Method described inadequately. Little description of data.
1	Very Poor	No mention of method, AND/OR Method inappropriate, AND/OR No details of data.

4. Sampling: Was the sampling strategy appropriate to address the aims?

4	Good	Details (age/gender/race/context) of who was studied and how they were recruited. Why this group was targeted. The sample size was justified for the study. Response rates shown and explained.
3	Fair	Sample size justified. Most information given, but some missing.
2	Poor	Sampling mentioned but few descriptive details.
1	Very Poor	No details of sample.

5. Data analysis: Was the description of the data analysis sufficiently rigorous?

4	Good	Clear description of how analysis was done. Description of how themes derived/ respondent validation or triangulation.
3	Fair	Descriptive discussion of analysis.

- | | | |
|---|-----------|---------------------------------|
| 2 | Poor | Minimal details about analysis. |
| 1 | Very Poor | No discussion of analysis. |
6. Ethics: Have ethical issues been addressed, and what has necessary ethical approval gained?
- | | | |
|---|-----------|---|
| 4 | Good | Where necessary issues of confidentiality, sensitivity, and consent were addressed. |
| 3 | Fair | Lip service was paid to above (i.e., these issues were acknowledged). |
| 2 | Poor | Brief mention of issues. |
| 1 | Very Poor | No mention of issues. |
7. Bias: Has the relationship between researchers and participants been adequately considered?
- | | | |
|---|-----------|---|
| 4 | Good | Researcher was reflexive and/or aware of own bias. |
| 3 | Fair | Lip service was paid to above (i.e., these issues were acknowledged). |
| 2 | Poor | Brief mention of issues. |
| 1 | Very Poor | No mention of issues. |
8. Results: Is there a clear statement of the findings?
- | | | |
|---|-----------|---|
| 4 | Good | Findings explicit, easy to understand, and in logical progression.
Tables, if present, are explained in text. Results relate directly to aims.
Sufficient data are presented to support findings. |
| 3 | Fair | Findings mentioned but more explanation could be given.
Data presented relate directly to results. |
| 2 | Poor | Findings presented haphazardly, not explained, and do not progress logically from results. |
| 1 | Very Poor | Findings not mentioned or do not relate to aims. |
9. Transferability or generalizability: Are the findings of this study transferable (generalizable) to a wider population?
- | | | |
|---|-----------|--|
| 4 | Good | Context and setting of the study is described sufficiently to allow comparison with other contexts and settings, plus high score in Question 4 (sampling). |
| 3 | Fair | Some context and setting described, but more needed to replicate or compare the study with others, PLUS fair score or higher in Question 4. |
| 2 | Poor | Minimal description of context/setting. |
| 1 | Very Poor | No description of context/setting. |
10. Implications and usefulness: How important are these findings to policy and practice?
- | | | |
|---|-----------|---|
| 4 | Good | Contributes something new and/or different in terms of understanding/insight or perspective.
Suggests ideas for further research.
Suggests implications for policy and/or practice. |
| 3 | Fair | Two of the above (state what is missing in comments). |
| 2 | Poor | Only one of the above. |
| 1 | Very Poor | None of the above. |

Appendix 4. Study Documentation



East of Scotland Research Ethics Service

Tayside Committee on Medical Research Ethics A

Research Ethics Office
TAHSC, Residency Block C
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Mrs Constantina/C Papadopoulos
PhD Student
11 Airlie Place
School of Nursing and Midwifery
University of Dundee
DD1 4HJ

Date: 30 September 2010
Your Ref:
Our Ref: **FB/LR/10/S1401/45**
Enquiries to: Miss Fiona Bain
Extension: Ninewells extension 32701
Direct Line: 01382 632701
Email: fionabain@nhs.net

Dear Mrs Papadopoulos

Study Title: Making sense of a diagnosis of Acute Leukaemia: a prospective, qualitative study
REC reference number: 10/S1401/45

Thank you for your letter of 22 September 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered by a sub-committee of the REC at a meeting held on 30 September 2010. A list of the sub-committee members is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

- Regarding the Participant Information Sheet – under 'What are the risks or disadvantages of taking part?' please delete 'of your being distressed'.

Please submit a revised version of the Participant Information Sheet, which should include a new version number and new full date.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.



Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Investigator CV		06 August 2010
Protocol	2.0	03 August 2010
CV - Dr Bridget Johnston		05 August 2010
REC application		05 August 2010
Covering Letter		09 August 2010
Letter from Sponsor		03 May 2010
Interview Schedules/Topic Guides - Patients	1.0	02 August 2010
Interview Schedules/Topic Guides – Family Caregiver	1.0	02 August 2010
GP/Consultant Information Sheets	2.0	29 April 2010
Response to Request for Further Information		22 September 2010
Participant Information Sheet: Patient	5.0	14 September 2010
Participant Information Sheet: Family Caregiver	5.0	14 September 2010
Participant Consent Form: Patient	5.0	14 September 2010
Participant Consent Form: Family Caregiver	5.0	14 September 2010
Case Report Form - Family Caregiver	2.0	02 August 2010
Case Report Form - Patient	2.0	02 August 2010
Copy of Unfavourable Opinion Letter		03 June 2010
Letter with regards to Committee Comments		09 August 2010
Evidence of insurance or indemnity		03 May 2010

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.



After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S1401/45 Please quote this number on all correspondence

Yours sincerely



for

Mr Carlos Wigderowitz
Chair

Enclosures:

List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to:

NHS Tayside R&D office





East of Scotland Research Ethics Service

Tayside Committee on Medical Research Ethics A

Research Ethics Office
TAHSC, Residency Block C
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Mrs Constantina/C Papadopolou
PhD Student
11 Airlie Place
School of Nursing and Midwifery
University of Dundee
DD1 4HJ

Date: **21 December 2010**
Your Ref:
Our Ref: LR/10/S1401/45
Enquiries to: Mrs Lorraine Reilly
Extension: Ninewells extension 40099
Direct Line: 01382 740099
Email: lorraine.reilly@nhs.net

Dear Mrs Papadopolou

Study Title: Making sense of a diagnosis of Acute Leukaemia: a prospective, qualitative study
REC reference number: 10/S1401/45
Amendment Number: AM01
Amendment Date: 15 December 2010

The above amendment was reviewed at the meeting of the Sub-Committee held on 21 December 2010.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Case Report Form - Family Caregiver	2.1	10 December 2010
Case Report Form - Patient	2.1	10 December 2010
GP/Consultant Information Sheets	2.1	10 December 2010
Participant Consent Form: Family Caregiver	2.1	10 December 2010
Participant Consent Form: Patient	6.1	10 December 2010
Participant Information Sheet: Family Caregiver	6.1	10 December 2010
Participant Information Sheet: Patient	6.1	10 December 2010
Protocol	2.1	09 December 2010
Notice of Substantial Amendment (non-CTIMPs)	01	15 December 2010
Covering Letter		15 December 2010



Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/S1401/45 Please quote this number on all correspondence

Yours sincerely



Mrs Lorraine Reilly
Sub-Committee Co-ordinator

Enclosures:	List of names and professions of members who took part in the review
Copy to:	NHS Tayside R&D office





East of Scotland Research Ethics Service

Tayside Committee on Medical Research Ethics A

Research Ethics Office
TAHSC, Residency Block C
Ninewells Hospital & Medical School
DUNDEE
DD1 9SY

Mrs Constantina/C Papadopoulou
PhD Student
11 Airlie Place
School of Nursing and Midwifery
University of Dundee
DUNDEE
DD1 4HJ

Date: 29 March 2011
Your Ref:
Our Ref: LR/10/S1401/45
Enquiries to: Mrs Lorraine Reilly
Extension: Ninewells extension 40099
Direct Line: 01382 740099
Email: lorraine.reilly@nhs.net

Dear Mrs Papadopoulou

Study Title: Making sense of a diagnosis of Acute Leukaemia: a prospective, qualitative study
REC reference number: 10/S1401/45
Amendment Number: AM02
Amendment Date: 22 March 2011

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

No ethical issues were noted and the members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
GP/Consultant Information Sheets - Tayside	3.0	21 March 2011
Participant Consent Form: Patient - Tayside	7.0	21 March 2011
Participant Consent Form: Family Caregiver - Grampian	7.1	21 March 2011
Participant Consent Form: Family Caregiver - Tayside	7.0	21 March 2011
Participant Consent Form: Patient - Grampian	7.1	21 March 2011
Participant Information Sheet: Family Caregiver - Grampian	7.1	21 March 2011
Participant Information Sheet: Family Caregiver - Tayside	7.0	21 March 2011
Participant Information Sheet: Patient - Grampian	7.1	21 March 2011
Participant Information Sheet: Patient - Tayside	7.0	21 March 2011
Protocol	3.0	



Notice of Substantial Amendment (non-CTIMPs)	02	22 March 2011
Covering Letter		22 March 2011
GP/Consultant Information Sheets - Grampian	3.1	21 March 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/S1401/45 Please quote this number on all correspondence

Yours sincerely


for **Dr Fergus Daly**
Alternate Vice-chair

Enclosures:

List of names and professions of members who took part in the review

Copy to:

NHS Tayside R&D office





AL/CF
3 May 2010
Dr Bridget Johnston
Senior Research Fellow
University of Dundee
School of Nursing and Midwifery
11 Airlie Place
Dundee
DD1 4HJ

Dear Dr Johnston

Sponsorship Letter for PhD Studentship: Ms Constantina Papadopoulou
Sponsor/NHS R&D Reference Number: 2010ON09
Study Title: Making sense of a diagnosis of Acute Leukaemia: A prospective qualitative study
Funder: Departmental/Self-funding
Sites: NHS Tayside

Under the requirements of the Scottish Executive Health Department Research Governance Framework for Health and Community Care, the University of Dundee agrees to act as Sponsor for this study effective from 1 April 2010. The University also confirms that Insurance cover for study design, and conduct of University of Dundee staff and the named postgraduate student is in place for this study. NHS Indemnity is provided via CNORIS.

Sponsorship is subject to you receiving favourable REC opinion and NHS Tayside R&D Management Approval.

As the Academic Supervisor, you must ensure that study recruitment only occurs at a clinical site once all applicable approvals are in place for that site.

You should ensure that any subsequent amendments are notified to the Sponsor, REC and relevant NHS R&D Office (s).

Please ensure that you and your research group are familiar with the applicable University of Dundee Standard Operating Procedures (available at <http://www.tahsc.org.uk>) and have current Good Clinical Practice training.

Finally please contact Dr Clark Crawford (c.w.crawford@dundee.ac.uk) or Dr Catrina Forde (c.forde@dundee.ac.uk) if you have any queries.

Yours sincerely

Dr Anne Langston
Senior R&D Manager
TAHSC

cc Ms. Constantina Papadopoulou, School of Nursing and Midwifery
Ms Jeannette Kalsgaard, RIS, UoD
Mrs Liz Coote, R&D Office, TAHSC



Professor Connell, TAHSC (Tayside Academic Health Sciences Centre)
T: 01382 20 20 20 | F: 01382 20 20 20 | E: Connell@dundee.ac.uk





EC/LH

19 October 2010

Mrs Constantina Papadopoulou
PhD Student
School of Nursing and Midwifery
University of Dundee
11 Airlie Place
DUNDEE
DD1 4HJ

Dear Mrs Papadopoulou,

NHS TAYSIDE MANAGEMENT/GOVERNANCE APPROVAL

Tayside R&D Project ID: 2010ON26

Title: Making sense of a diagnosis of acute leukaemia: a prospective, qualitative study.

Main REC Ref: 10/S1401/45 Main REC Approval Date: 30/09/10

Funder: Unfunded

Sponsor: University of Dundee

NHS Support Costs: Yes

The above project has been registered on the NHS Tayside R&D database, as required by the Research Governance Framework. Medical Research Ethics approval has been obtained and there are local NHS Support Costs associated with this research project.

NHS Tayside has no objection to the project proceeding, provided all necessary approvals are in place and all amendments to the protocol, personnel involved and funding be notified to the R&D Office and all appropriate personnel. **Please note notification of end of study and a copy of the end of study report is also required by the NHS R&D office.**

It is important to note that all research must be carried out in compliance with the Research Governance Framework for Health & Community Care, GCP and the new EU Clinical Trials Directive (for clinical trials involving investigational medicinal products).

Kind Regards

A handwritten signature in black ink that reads 'Elizabeth Coote'.

Elizabeth Coote
R&D Manager

Research and Development

Foresterhill House Annexe
Foresterhill
Aberdeen
AB25 2ZB



Mr Jeff Horn
MacMillan Clinical Nurse
Specialist
Haematology Day Unit
Aberdeen Royal Infirmary
Westburn Road
Aberdeen
AB25 2ZN

Date 18/01/11
Our Ref 2010ON023

Enquiries to
Extension 51121
Direct Line 01224 551121

Dear Mr Horn

Management Approval for Non-Commercial Research

REC Ref: 10/S1401/45
NRS Ref: NRS10/HA16
Project title: Making sense of a diagnosis of acute leukaemia: a prospective, qualitative study

Thank you very much for sending all relevant documentation. I am pleased to confirm that the above project is now registered with the NHS Grampian Research & Development Office. The project now has R & D Management Approval to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place. This letter also confirms R&D approval for amendment AM01 dated 15/12/10.

All research with an NHS element is subject to the Research Governance Framework for Health and Community Care (2006, 2nd edition), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

It is particularly important that you inform us when the study terminates.

The R&D Office must be notified immediately and any relevant documents forwarded to us if any of the following occur:

- A change of Principal Investigator, Chief Investigator or any additional research personnel
- Premature project termination
- Any amendments (particularly a study extension)
- Any change to funding or any additional funding

We hope the project goes well, and if you need any help or advice relating to your R&D Management Approval, please do not hesitate to contact the office.

Yours sincerely

Susan Ridge
Business Development Officer

Cc: Mrs Constantina Papadopoulou, Chief Investigator, University of Dundee
NHS Research Scotland Permissions Co-ordinating Centre (NRS Permissions CC)

Making sense of a diagnosis of acute leukaemia: a qualitative study



School of
NURSING AND MIDWIFERY



PARTICIPANT INFORMATION SHEET – PATIENT

STUDY TITLE

Making sense of a diagnosis of acute leukaemia: a prospective, qualitative study

INVITATION

My name is Constantina Papadopoulou and I am a PhD student at the University of Dundee. I am doing a project as part of my course and invite you to take part in the following study. However, before you decide to take part, I am therefore providing you with the following information so that you understand firstly why I am doing the study, and secondly what it would involve if you agreed to take part. Please read this sheet carefully and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any answers to your queries and any further information you may ask for now or later.



What is the purpose of this study?

The purpose of this study is to understand what it is like for people and their families to live with a diagnosis of acute leukaemia. We are interested to know more about patients' and their families' understandings of leukaemia and how this illness can affect their lives. Results from this study will help health professionals to develop interventions in order to provide better care to people diagnosed acute leukaemia.

Why have I been chosen?

You have been chosen because you have been diagnosed with acute leukaemia. We would like to have a maximum of 10 patients and 10 carers taking part in the study.

Do I have to take part?

Taking part in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your future medical care or your relationship with the medical and nursing staff looking after you.

However, any information provided until that moment will be included in the study without revealing any of your personal information.

What will happen to me if I take part?

If you agree to take part, you will meet the researcher who is conducting this study, who will ask to interview you 2 times over a period of approximately 4 weeks.



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If you do decide to take part, you will be asked to nominate your family caregiver (i.e. a family member, who provides care and support to you) as they will also be invited to take part in the study.

The first interview will take place after you have agreed to take part at a location most convenient for you. This can be either a private room in the hospital or your home. If your interview is being conducted at the hospital, the researcher will try to arrange this at a time that you will be attending the hospital for another appointment. The second interview will take place 2 to 4 weeks later in order to further discuss issues from the first interview.

What will my responsibilities in the study be?

Throughout your participation you will be asked to give information in the form of a discussion with the researcher about your understandings of your diagnosis and your experiences during your chemotherapy treatment.

If you are interested in taking part in the study, an appointment will be arranged with the researcher (in collaboration with your nurse) 48 hours after your nurse has given you this information sheet and your carer in order to explain to you more about the study. If you agree to take part, she will give you an informed consent to sign and arrange when and where you will meet for the first interview.

The researcher will first ask you to talk about what your diagnosis means to you. She will then ask you to talk about your life and your experiences since being diagnosed with leukaemia. It is expected that this discussion will take around an hour to complete. If you agree, the researcher will record the interview, to make sure there is an accurate account of what you have discussed. Transcripts will be stored securely at the University of Dundee and no-one apart from the researcher and her two supervisors will have access to them.

At the end of the first interview, the researcher will ask you if you would agree to be interviewed 2-4 weeks later to discuss in depth any of the issues raised during the first interview or any new matters that may arise. If you do not want to take part in a further interview, you will be thanked for your time and your treatment or care will not be affected in anyway.

If you do agree, the researcher will begin the next interview by feeding back her thoughts on the last interview; this is to allow you to remember what were the issues discussed in the previous interview.

This table shows how many times you will be contacted during the study:

1 st interview	The following days after you have agreed to take part.
2 nd interview	2-4 weeks after the 1 st interview.



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What are the risks or disadvantages of taking part?

As you will be talking about what your illness means to you, your life and experiences of being diagnosed with acute leukaemia, you may find this upsetting. If during the interviews you feel distressed, then the interview will be stopped. A debriefing discussion will follow with the researcher. Then, with your permission, your Consultant, Dr. Kerr, and your Clinical Nurse Specialist, Mrs Grace Fitzsimmons, will be contacted by the researcher and will be given a brief update. You will have the opportunity to discuss your worries and feelings with either of them. In case a member of your health care team finds appropriate may seek for further assistance from the specialist that collaborates with the team.

What are the possible benefits of taking part?

Your taking part in this study will give you the chance to talk about what you think about your illness and express what you have experienced as a result of it. The study may help other people diagnosed with acute leukaemia in the future by helping us to understand people's perceptions and develop ways in which we can help them cope better with their illness.

What if new information becomes available?

Sometimes during the course of a research project new information becomes available related to the study process. If this happens, the researcher will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw, your treatment and care will continue as normal. This will not be affected in any way. If you decide to continue in the study you (and your carer) might be asked to sign an updated informed consent form. Also, on receiving new information, your doctor or nurse might consider it to be in your best interests to withdraw you from the study. He/she will explain the reasons.

Are there any circumstances and/or reasons under which my participation in the study may be terminated?

Your participation is solely based on your willingness to take part and is entirely voluntary. If however you become too emotional and upset during the interviews, your participation in the study will be re-evaluated for your own benefit by the researcher and your health care team (ie. your Consultant, Dr. Kerr, and your Clinical Nurse Specialist, Mrs Grace Fitzsimmons). If any of the members of your health care team or the researcher finds that your participation is more burdensome than constructive then your participation in the study will be terminated.

Will I be paid to take part?

No.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (Constantina Papadopolou – 01382 384968). Any complaints that you have about this study should be addressed initially to your doctor or nurse. If you do not get a satisfactory response from them you are free to contact the organisers of this research at the address below.

Making sense of a diagnosis of acute leukaemia: a qualitative study



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Dr Catrina Forde
Tayside Academic Health Sciences Centre
Ninewells Hospital & Medical School
TAHSC Research & Development Office
Residency Block, Level 2
George Pirie Way
Dundee, United Kingdom
DD1 9SY
Email: c.forde@dundee.ac.uk
Tel: 01382 740125

If you are harmed due to someone's negligence, then you may have grounds for legal action to **claim compensation** but you may have to pay for it. If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints procedure mechanisms may be available to you. Your doctor will give you further information if necessary.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of research will be kept strictly confidential. All audio tapes will be erased as soon as they are transcribed. No-one will be able to recognise you from any report about the study – your name and anything which could lead to anyone being able to identify you will be removed.

If you decide to take part, the signed Informed Consent Form will be kept separately from any other information you provide and will be stored in a locked drawer for the Researcher's use only and will not be shared with anyone else.

What will happen to the results of the study?

The information you provide will be used to draw general conclusions on how people make sense of their diagnosis of acute leukaemia. The results of the study will then be used for research and education purposes (including reports, publications and presentations) with strict preservation of your anonymity.

Who is organising and funding the study?

The study is being organised by the University of Dundee. It is being funded by a PhD Student Grant.

Who has reviewed this study?

The Tayside Committee on Medical Research Ethics, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from University of Dundee, NHS Tayside and the

Making sense of a diagnosis of acute leukaemia: a qualitative study



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Regulatory Authorities, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Contact for further information?

Should you wish any further information about the study, please contact the researcher or her supervisors below:

Researcher – PhD Student

Constantina Papadopoulou
School of Nursing & Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 384968
Fax: 01382 388533
Email: c.z.papadopoulou@dundee.ac.uk

1st Supervisor

Dr Bridget Johnston
Senior Research Fellow
School of Nursing & Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 388505
Fax: 01382 388533
Email: b.johnston@dundee.ac.uk

2nd Supervisor

Dr. Markus Themessl-Huber
Senior Research Fellow
Dental Health Services Research Unit (DHSRU)
University of Dundee, Mackenzie Building
Kirsty Semple Way, Dundee DD2 4BF
Tel: 01382 420140
Fax: 01382 420051
Email: M.Themessl-Huber@cpse.dundee.ac.uk

3rd Supervisor

Professor Nora Kearney
School of Nursing & Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 388532
Fax: 01382 388533
Email: n.kearney@dundee.ac.uk

If you would like to speak about a problem or a complaint you have to someone who knows about this study who is an independent advisor, please contact:

Independent Advisor

Roma Maguire
Senior Research Fellow
School of Nursing and Midwifery
University of Dundee

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11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 384965
Fax: 01382 388533
Email: r.z.maguire@dundee.ac.uk

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.





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PARTICIPANT INFORMATION SHEET – FAMILY CAREGIVER

STUDY TITLE

Making sense of a diagnosis of acute leukaemia: a prospective, qualitative study

INVITATION

My name is Constantina Papadopoulou and I am a PhD student at the University of Dundee. I am doing a project as part of my course and invite you to take part in the following study. However, before you decide to take part, I am therefore providing you with the following information so that you understand firstly why I am doing the study, and secondly what it would involve if you agreed to take part. Please read this sheet carefully and, if you want, discuss it with others including your friends and family. I will do my best to explain the project to you and provide you with any answers to your queries and any further information you may ask for now or later.



What is the purpose of this study?

The purpose of this study is to understand what it is like for people and their families to live with a diagnosis of acute leukaemia. We are interested to know more about patients' and their families' understandings of leukaemia and how this illness can affect their lives. Results from this study will help health professionals to develop interventions in order to provide better care to people diagnosed acute leukaemia.

Why have I been chosen?

You have been chosen because you have been nominated as the carer by a family member diagnosed with acute leukaemia. We want to have a maximum of 10 patients and 10 carers taking part in the study.

Do I have to take part?

Taking part in this study is entirely voluntary and you are free to refuse to take part or to withdraw from the study at any time without having to give a reason and without this affecting your future medical care or your relationship with medical and nursing staff looking after you.

However, any information provided until that moment will be included in the study without revealing any of your personal information.

What will happen to me if I take part?

If you agree to take part, you will meet the researcher who is conducting this study, who will ask to interview you 2 times over a period of approximately 4 weeks.



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The first interview will take place after you have agreed to take part at a location most convenient for you. This can be either a private room in the hospital or your home. If your interview is being conducted at the hospital, the researcher will try to arrange this at a time that you will be attending the hospital for another appointment. The second interview will take place 2 to 4 weeks later in order to further discuss issues from the first interview.

What will my responsibilities in the study be?

Throughout your participation you will be asked to give information in the form of a discussion about your understandings of your family member's diagnosis and your experiences during chemotherapy.

If you are interested in taking part in the study, an appointment will be arranged with the researcher (in collaboration with your nurse) 48 hours after the nurse has given you this information sheet, and your family member in order to explain to you more about the study. If you agree to take part, she will give you an informed consent to sign and you will both arrange when and where you will meet for the first interview.

The researcher will first ask you to talk about in detail what your family member's diagnosis means to you. She will then ask you to talk about your life and your experiences since caring for someone diagnosed with leukaemia. It is expected that this discussion will take around an hour to complete. If you agree, the researcher will record the interview, to make sure there is an accurate account of what you have discussed. Transcripts will be stored securely at the University of Dundee and no-one outside the researcher and her two supervisors will have access to them.

At the end of the first interview, the researcher will ask you if you would agree to be interviewed 2-4 weeks later to discuss in depth any of the issues raised during the first interview or any new matters that may arise. If you do not want to take part in a further interview, you will be thanked for your time and your treatment or care will not be affected in anyway.

If you do agree, the researcher will begin the next interview by feeding back her thoughts on the last interview; this is to allow you to remember what were the issues discussed in the previous interview.

This table shows how many times you will be contacted during the study:

1 st interview	The following days after you have agreed to take part.
2 nd interview	2-4 weeks after the 1 st interview.

What are the risks or disadvantages of taking part?

In no way your taking part in the study will affect your ability to provide care to your family member, nor will cause any additional expenses to you (or your family member).



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However, giving information about your personal experience might become upsetting. As you will be talking about what the illness means to you, your life and experiences of taking care of someone with acute leukaemia, you may find this upsetting. If during the interviews you feel distressed, then the interview will be stopped. A debriefing discussion will follow with the researcher. Then, with your permission, your Consultant, Dr. Culligan, and your Clinical Nurse Specialist, Mr Jeff Horn, will be contacted by the researcher and will be given a brief update. You will have the opportunity to discuss your worries and feelings with either of them. In case a member of your health care team finds appropriate may seek for further assistance from the specialist that collaborates with the team.

What are the possible benefits of taking part?

Your taking part in this study will give you the chance to say what you think about this illness and express what you have experienced as a result of it. The study may help other people diagnosed with acute leukaemia and their carers in the future by helping us to understand people's perceptions and develop ways in which we can help them better cope with serious illness.

What if new information becomes available?

Sometimes during the course of a research project new information becomes available related to the study process. If this happens, the researcher will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw, your family member's treatment and care will continue as normal. This will not be affected in any way. If you decide to continue in the study you (and your family member) might be asked to sign an updated informed consent form. Also, on receiving new information, the family member's doctor or nurse might consider it to be in your best interests to withdraw you from the study. He/she will explain the reasons.

Are there any circumstances and/or reasons under which my participation in the study may be terminated?

Your participation is solely based on your willingness to take part and is entirely voluntary. If however you become too emotional and upset during the interviews, your participation in the study will be re-evaluated for your own benefit by the researcher and your health care team (ie. your Consultant, Dr. Culligan, and your Clinical Nurse Specialist, Mr Jeff Horn). If any of the members of your health care team or the researcher finds that your participation is more burdensome than constructive then your participation in the study will be terminated.

Will I be paid to take part?

No.

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions (Constantina Papadopoulou – 01382 384968). Any complaints that you have



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about this study should be addressed initially to your doctor or nurse. If you do not get a satisfactory response from them you are free to contact the sponsors of this research at the address below.

Dr Catrina Forde
Tayside Academic Health Sciences Centre
Ninewells Hospital & Medical School
TAHSC Research & Development Office
Residency Block, Level 2
George Pirie Way
Dundee, United Kingdom
DD1 9SY
Email: c.forde@dundee.ac.uk
Tel: 01382 740125

If you are harmed due to someone's negligence, then you may have grounds for legal action to **claim compensation** but you may have to pay for it. If you wish to complain about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints procedure mechanisms may be available to you. Your doctor will give you further information if necessary.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of research will be kept strictly confidential. All audio tapes will be erased as soon as they are transcribed. No-one will be able to recognise you from any report about the study – your name and anything which could lead to anyone being able to identify you will be removed.

If you decide to take part, the signed Informed Consent Form will be kept separately from any other information you provide and will be stored in a locked drawer for the Researcher's use only and will not be shared with anyone else. Also a copy of the Informed Consent Form will be given to the health care team to keep with the family member's casenotes.

What will happen to the results of the study?

The information you provide will be used to draw general conclusions on how patients and their informal carers make sense of a diagnosis of acute leukaemia. The results of the study will then be used for research and education purposes (including reports, publications and presentations) with strict preservation of your anonymity.

Who is organising and funding the study?

The study is being organised by the University of Dundee. It is being funded by a PhD Student Grant. Your hospital is not being paid to include you in this study.



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Who has reviewed this study?

The Tayside Committee on Medical Research Ethics, which has responsibility for scrutinising all proposals for medical research on humans in Tayside, has examined the proposal and has raised no objections from the point of view of medical ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from University of Dundee, NHS Tayside and the Regulatory Authorities, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Contact for further information?

Should you wish any further information about the study, please contact the researcher or her supervisors below:

Researcher – PhD Student

Constantina Papadopoulou
School of Nursing & Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 384968
Fax: 01382 388533
Email: c.z.papadopoulou@dundee.ac.uk

1st Supervisor

Dr Bridget Johnston
Senior Research Fellow
School of Nursing & Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 388505
Fax: 01382 388533
Email: b.johnston@dundee.ac.uk

2nd Supervisor

Dr. Markus Themessl-Huber
Senior Research Fellow
Dental Health Services Research Unit (DHSRU)
University of Dundee, Mackenzie Building
Kirsty Semple Way, DUNDEE DD2 4BF
Tel: 01382 420140
Fax: 01382 420051
Email: M.Themessl-Huber@cpse.dundee.ac.uk

3rd Supervisor

Professor Nora Kearney
School of Nursing & Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 388532
Fax: 01382 388533
Email: n.kearney@dundee.ac.uk

Making sense of a diagnosis of acute leukaemia: a qualitative study



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If you would like to speak about a problem or a complaint you have to someone who knows about this study who is an independent advisor, please contact:

Independent Advisor

Roma Maguire
Senior Research Fellow
School of Nursing and Midwifery
University of Dundee
11 Airlie Place, DUNDEE DD1 4HJ
Tel: 01382 384965
Fax: 01382 388533
Email: r.z.maguire@dundee.ac.uk

Thank you for taking the time to read this Information Sheet and for considering taking part in this study.





PARTICIPANT INFORMED CONSENT FORM – PATIENT

STUDY TITLE

Making sense of a diagnosis of acute leukaemia; a qualitative study

Please take time to read the following statements. If you agree with the statement, please put your initials in the box thus providing your consent.

Statement	Initial
I confirm that I have read and understand the Study Information Sheet dated on 21 March 2011 [Version 7.1] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand the nature and purpose of the study.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical treatment, care or legal rights being affected.	
I understand that interviews will be tape recorded. It has been explained to me that the audio tapes will be destroyed as soon as they are transcribed. It has been explained to me that transcripts of the tapes will be stored securely for 5 years and I will not be identified by anyone except for the researcher. The information will be destroyed after this time.	



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I understand that if I choose to withdraw from the study or become unable to consent during the study, any information provided till this moment will be included in the study, with my personal data remaining confidential.		
I understand that this form will be kept separately from any other information that I provide and will be stored in a locked drawer for the Researcher's use only and will not be shared with anyone else.		
I give permission for the information I provide to be used for research purposes (including reports, publications and presentations), with strict preservation of anonymity.		
I agree to my Consultant being notified by letter of my participation in this project.		
I agree to take part in the above-mentioned study.		
_____	_____	_____
Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature



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PARTICIPANT INFORMED CONSENT FORM – FAMILY CAREGIVER

STUDY TITLE

Making sense of a diagnosis of acute leukaemia; a qualitative study

Please take time to read the following statements. If you agree with the statement, please put your initials in the box thus providing your consent.

Statement	Initial
I confirm that I have read and understand the Study Information Sheet dated on 21 March 2011 [Version 7.0] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
I understand the nature and purpose of the study.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my decision affecting medical treatment, care or legal rights of the patient I care for.	
I understand that interviews will be tape recorded. It has been explained to me that the audio tapes will be destroyed as soon as they are transcribed. It has been explained to me that transcripts of the tapes will be stored securely for 5 years and I will not be identified by anyone except for the researcher. The information will be destroyed after this time.	
I understand that if I choose to withdraw from the study or	

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become unable to consent during the study, any information provided till this moment will be included in the study, with my personal data remaining confidential.		
I understand that this form will be kept separately from any other information that I provide and will be stored in a locked drawer for the Researcher's use only and will not be shared with anyone else.		
I give permission for the information I provide to be used for research purposes (including reports, publications and presentations), with strict preservation of my anonymity.		
I agree to take part in the above-mentioned study.		
_____	_____	_____
Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

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LETTER TO GP/CONSULTANT

Dear Dr

Your patient has agreed to take part in a PHD research study entitled “Making sense of Acute Leukaemia: a qualitative study”. The study has been organised by the School of Nursing and Midwifery at the University of Dundee.

The study aims to explore patients’ and their informal caregivers’ meanings of living with acute leukaemia. The patient has agreed to be interviewed up to 2 times over a period of approximately 4 weeks.

If you require further information or have any questions, please do not hesitate to contact me by telephone on 01382 384968 or email c.z.papadopoulou@dundee.ac.uk.

Yours sincerely,

Constantine Papadopoulou
BSN, MSc, PhD student
2009-2011 Rotary Ambassadorial Scholar
University of Dundee,
School of Nursing & Midwifery
11 Airlie Place,
Dundee, DD1 4HJ

MAKING SENSE OF ACUTE LEUKAEMIA – INTERVIEW GUIDE

Physical aspects

How did you find out about your illness? What happened? What brought you in hospital?

How have you been during the time you were in hospital? How was your chemotherapy?

(Optional: Health care professionals) How was life in the ward? Do you remember an example to share?

What does it mean to you?

What does it mean about you?

Emotional aspect

How did you feel when you were announced that you have leukaemia?

How do you feel now?

Mental aspect

What were your first thoughts when you heard your diagnosis?

What are your thoughts now?

Support system/ Family – friends

How about your family? How did they learn about your illness?

What do you think about them?

How has your illness affected your relationship with them? What are you thought? How do you feel about it?

What about your friends?

What does it mean to you to get support by them (family/friends)? What does tell about you?

Coping styles

In the past how would you cope with difficult situations? Can you share an example of a difficult situation and how you coped with it?

How do you cope now with your illness?

Past

Have you ever heard about leukaemia before?

Future

How do you see yourself in the future?

Reflection Sheet

Patient ID:		Date:	
Site:		Number of Interview:	

What were the main issues or themes that stuck you in this contact?

Summary of the information collected.

Anything else that struck you as salient, interesting, illuminating or important in this contact?

How did you feel when doing the interview?

Reflection Sheet

Any other thoughts/ comments regarding the interview?

GRP03 1st interview

Emergent Themes	Original Transcript	Exploratory Comments
<p>Leukaemia hard to make sense</p> <p>Surprise diagnosis</p> <p>Leukaemia in disguise with infection</p> <p>General knowledge as frame of reference</p>	<p>1. CP: Em first of all I'd like to thank you for taking the time to speak with me</p> <p>2.</p> <p>3.</p> <p>4. P: That's quite alright</p> <p>5.</p> <p>6. CP: Em, eh, you have to remember there is em, there are no right and wrong answers</p> <p>7.</p> <p>8.</p> <p>9. P: I understand</p> <p>10.</p> <p>11. CP: Em, and eh if at any case eh, or at any time during the interview you feel like stopping the voice recorder or you know, stopping it at all you're, you're free to do so, that's fine</p> <p>12.</p> <p>13.</p> <p>14. ...</p> <p>15.</p> <p>16. P: Yeah I understand that</p> <p>17.</p> <p>18. CP: Eh, oh right, so ... eh the first thing I'd like to ask you is em, what does it mean to have, to ... what does it mean to you to have acute leukaemia?</p> <p>19.</p> <p>20.</p> <p>21.</p> <p>22. P: [sighs] Em ... I don't really know. It's ... as, as, as I said, this is the second time I've, I've got it and the first time eh I was told, I was really, really ill at the time and em, I had no idea it was going to be sort of cancerous or anything, I just thought it was just some really bad bug I had, and em I got a phone call from the hospital, 'cause I had given a blood test and eh the first thing he said was "oh there's unusual white cells in your blood,</p> <p>23.</p> <p>24.</p> <p>25.</p> <p>26.</p> <p>27.</p> <p>28.</p>	<p>He doesn't know what it means to have leukaemia.</p> <p>Taken by surprise. Having no clue.</p> <p>Leukaemia in disguise with infection.</p> <p>A simple blood test leading to a cancer diagnosis. General knowledge as frame of reference.</p>

<p>Smoking as a cause of leukaemia The 'prisoner' – leukaemia as punishment</p> <p>Knowledge as frame of reference Self-blame</p> <p>Shock of diagnosis Coping efforts Dream, unreal world Denial</p> <p>Power Coping strategy Positive attitude</p> <p>Cognitive decision to cope</p>	<p>29. could you come into hospital?", and as soon as he said that I</p> <p>30. knew it was sort of ... cancer-related</p> <p>31.</p> <p>32. CP: Mmm</p> <p>33.</p> <p>34. P: Em, I've been a heavy smoker for 25 years ... 30 years ... and</p> <p>35. my first thought was ... [claps hands together] - "<i>I've been</i></p> <p>36. <i>caught</i>" ...</p> <p>37.</p> <p>38. CP: Mmm</p> <p>39.</p> <p>40. P: ... you know I, I know the dangers of like smoking, you know</p> <p>41. smoking's related to sort of disease and I, I'd sort of just initially</p> <p>42. thought well it's my own fault, you know I, I know the risks,</p> <p>43. "I've got cancer now", but as it turns out they don't think that</p> <p>44. leukaemia has got any relation to, to smoking diseases so, but</p> <p>45. ... it was, it was a bit of a shock. Once, once I, I got in here and</p> <p>46. I've got a bit better it was really hard to sort of come to terms</p> <p>47. with. You know a lot of it was, almost like in a dream world,</p> <p>48. you know it's like "is this really happening?", I'll, I'll just wake</p> <p>49. up and it's a bad dream, but – <i>no</i> ... but within, I don't know the</p> <p>50. first couple of weeks em, I just decided well if I'm going to beat</p> <p>51. this disease, I'm going to have to sort of buck myself up and</p> <p>52. have a really positive attitude and that's what I did. E-h, and it</p> <p>53. seemed to have worked through my first treatment</p> <p>54.</p> <p>55. CP: How long before was that?</p> <p>56.</p> <p>57. P: That was eh about a year ago</p> <p>58.</p> <p>59. CP: A year ago</p> <p>60.</p>	<p>Smoking related to cancer.</p> <p>Sense of guilt. 'I've been caught': suggestive gem</p> <p>Illness perceptions/previous knowledge of cancer.</p> <p>Self-blame They don't think: Does he think it then? Maybe <i>he</i> relates smoking to leukaemia.</p> <p>Leukaemia was difficult to accept</p> <p>Sense of living in an unreal world.</p> <p>Denial. Personal decision: he has to be positive. Positive attitude as a coping mechanism. Initial timeline: shock → denial/dream world → personal decision: adopting a positive attitude. What was it that made him change his coping style then? He needed to protect himself in a way?</p>
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<p>Avoidance as a protective mechanism Cognitive decision Positive attitude Patient surrendering to experts Positive attitude</p> <p>Being hopeful</p> <p>General knowledge as reference to understand</p> <p>General knowledge as reference to understand</p>	<p>61. P: Yeah</p> <p>62.</p> <p>63. CP: M-mmm</p> <p>64.</p> <p>65. P: Well sorry it's, it's a [coughs], I went in in February 2010 and</p> <p>66. I came out in the end of June 2010, after my, my treatment and</p> <p>67. I was given the sort of "all clear" eh to go, and em ... I, I didn't</p> <p>68. try to ... wallow too much on it, I just thought right just be</p> <p>69. positive, you know ... the doctors here, they know exactly what</p> <p>70. they're doing, eh, just let them get on with it and just, you</p> <p>71. know just try and be as eh positive about it and, you know any</p> <p>72. little sort oh blips I had, I would just say "well, OK I'm having a</p> <p>73. wee blip, but I will get better" and stuff like that</p> <p>74.</p> <p>75. CP: Mmm. Why, you said something interesting, when, when</p> <p>76. you got the blood test, em and you got the phone call back,</p> <p>77. you thought it was cancer, how, how ... I mean that was what</p> <p>78. ... ?</p> <p>79.</p> <p>80. P: It's just the, the fact that, before he was going on about</p> <p>81. unusual white cells, I'm not a doctor but I do have general sort</p> <p>82. of knowledge of things ...</p> <p>83.</p> <p>84. CP: M-mmm</p> <p>85.</p> <p>86. P: ... so I knew that that is usually related to some sort of</p> <p>87. cancerous disease ...</p> <p>88.</p> <p>89. CP: M-mmm, m-mmm, oh right, OK</p> <p>90.</p> <p>91. P: ... em, just like I say I, I, I'm a great sort oh sponge of</p> <p>92. knowledge and I pick up these sort of bits and pieces ...</p>	<p>Blocking of emotions/thoughts as a self-protecting act Denial as protective coping style Being positive as a coping mechanism. Patient surrendering to the experts.</p> <p>Blip as adversity/difficult times during the illness journey.</p> <p>Being positive, optimistic.</p> <p>Previous general knowledge as frame of reference Old frames of reference.</p>
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<p>Vs.</p> <p>Specific experience as reference to understand</p> <p>Leukaemia is hard to make sense</p> <p>Separating from father's illness</p> <p>The illness and comorbidities</p> <p>Understanding experimental treatments</p> <p>Contrasting image: self-blame vs. it is treatable/hope</p>	<p>93.</p> <p>94. CP: Oh right, OK</p> <p>95.</p> <p>96. P: ... also the fact is my father had, had the disease a couple of</p> <p>97. years before me so I was aware eh, a bit more maybe than the,</p> <p>98. the normal person in the street</p> <p>99.</p> <p>100. CP: Mmm, I see. And, did your experience with your dad [?] well, influenced how you coped with your diagnosis?</p> <p>101.</p> <p>102.</p> <p>103. P: [slight pause] E-m ... I, I, I don't know. Em, because by the</p> <p>104. time my father had come in here he was quite ill with other</p> <p>105. complications, so he was quite a poorly man when he came in</p> <p>106. here, and ... he was put on ... he was put on eh, what they said</p> <p>107. was experimental treatments ...</p> <p>108.</p> <p>109. CP: U-uhh</p> <p>110.</p> <p>111. P: ... which, to my mind means there's, they don't really know</p> <p>112. how to fix it, we will, we'll try this and I thought, well ... you</p> <p>113. know I don't think my father's going to survive this, you know,</p> <p>114. eh, 'cause he was quite bad with it to, well subsequently you</p> <p>115. know as it turned out, that's what happened</p> <p>116.</p> <p>117. CP: Mmm. Did you, did you think that, what did you think, what were your thoughts when you heard that you have leukaemia?</p> <p>118.</p> <p>119.</p> <p>120.</p> <p>121. P: When I first heard it?</p> <p>122.</p> <p>123. CP: M-mmm</p> <p>124.</p>	<p>Old frame of reference: previous experience with leukaemia: his father died of leukaemia</p> <p>Comparing the two experiences of leukaemia: he was different from his father: reasoning differences</p> <p>Comorbidities and leukaemia</p> <p>Experimental treatments other treatment → not with curative intent</p> <p>Experimental = there is no cure = he will die</p>
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Initial thoughts (resignation)	125. P: Like I say the very first thought was a sort of resignation that	
Cancer/health perceptions	126. because of ... my unhealthy habits had caught up with me and	
Self-blame	127. part of me was like, well it's your own fault. You, you, you	
Hope in treatment	128. know that what you were doing can damage your body, it's	
Depression	129. happened, you know ... so part of that was, you know sort of	
Cognitive decision to cope	130. resigned to the fact that well that's my fault, and then the	
Positive attitude	131. other half was, well ... this is not a absolute killer, there is ways	
Autosuggestion as coping	132. and means out of this. 'Cause eh I was a, a wee bit depressed	
Denial as protecting mechanism	133. obviously you know for a while, then that's when I said, "well	
Stoicity	134. no, I'll just have to buck up here, be positive and ...", you know	
	135. "just try and fight it", I haven't, eh, I didn't really give it a <i>lot</i> of	
	136. deep thought, it was just like, " <i>just think about getting better,</i>	
	137. <i>think about getting better</i> ", you know. So I didn't sort of	
	138. wallow and "oh God ... I'm going to die ...", or "I'm going to be	
	139. disabled for the rest of my life", you know I just thought ...	
	140. "let's just get on with this", and sort it out	
	141.	
	142. CP: Mmm. And how was treatment for you?	
	143.	
Fear of treatment	144. P: E-m ... the treatment was, was, was good. Em, you know I've	
Preconceptions of chemotherapy	145. heard horror stories of chemo you know being really nasty to	
...side effects	146. your body and em ... but I didn't have any really bad reactions.	
	147. Obviously you know my ... I lost a lot of body hair but that	
	148. doesn't really bother me, eh a great deal. Em ... and it made	
Fatigue as side effect from treatment	149. me physically very, very weak. But other than that it, you know	
	150. I didn't have any major side-effects and I, I thought I was, you	
	151. know I, I was quite lucky 'cause, when you're in this ward you	
Hospital, a new society	152. get moved around quite a lot and you meet lots of people on	
	153. different regimes and stuff and, you know I'd look at some	
Perceptions on treatment	154. people and I'd go "oh my God", you know they're so poorly yet,	
	155. you know I'm sitting there, 'cause I was getting steroids and I	
	156. was quite fat and chubby and everybody going "oh you look	
		<p>Illness perceptions/attitudes</p> <p>Self-blame/guilt</p> <p>Initial thoughts: (1) I did it to myself; (2) it can be cured</p> <p>2 forces: (1) Guilt; (2) Hope/fighting spirit</p> <p>Leukaemia impacts on mood. Depression as a consequence of leukaemia</p> <p>Avoidance as a protective mechanism</p> <p>Autosuggestion → type of meditation. The Coué method.</p> <p>Fighting spirit</p> <p>Being stoic</p> <p>Practical coping</p> <p>Horror stories of chemotherapy: a treatment that can cause fear in a sense. Treatment is worse than the illness itself.</p> <p>Previous knowledge on chemotherapy. Fear – chemo</p> <p>Reality of chemotherapy not too bad: hair loss/fatigue: main side-effects</p> <p>What are major side-effects?</p> <p>Hospital social life/hospital a new society</p> <p>Perceptions on illness/chemo: it makes you look sick, it makes you sad, it makes you look poorly. The image of a 'chubby' fat person is not the picture of a patient with cancer.</p>

<p>Perceptions on treatment</p>	<p>157. really healthy”, and I was going ... feeling a bit guilty, you know</p> <p>158. 'cause everybody is just, you know really sort oh sallow and</p> <p>159. sad, but ...</p> <p>160.</p> <p>161. CP: What would be, what, what would you consider to be the,</p> <p>162. the, the serious side-effects? You said you didn't have any</p> <p>163. serious side what ...</p> <p>164.</p> <p>165. P: Yeah ...</p> <p>166.</p> <p>167. CP: ... serious [?] ...</p> <p>168.</p> <p>169. P: ... like I, I don't know. To be honest maybe a reaction to the</p> <p>170. ... you know to the chemo or something. I mean I did, I did take</p> <p>171. 6 a reaction to a bag of platelets ...</p> <p>172.</p> <p>173. CP: Mmm ...</p> <p>174.</p> <p>175. P: ... eh and my ...</p> <p>176.</p> <p>177. CP: ... allergic ...</p> <p>178.</p> <p>179. P: ... allergic reaction ...</p> <p>180.</p> <p>181. CP: Yeah, yeah</p> <p>182.</p> <p>183. P: ... and my throat, face swole [swelled] up and I got you know</p> <p>184. lumps and bumps but you know a quick Piriton injection and</p> <p>185. half an hour later was better</p> <p>186.</p> <p>187. CP: M-mmm</p> <p>188.</p>	<p>He was different from the others and what would so picture as a cancer patient.</p> <p>Why is he saying this: his 'healthy' image made him different from the croud.</p> <p>Major side effects: reaction to chemo: is hair loss and fatigue</p> <p>Considered as something else then?</p> <p>He might mean allergic reaction (as he gives an example) or the chemo not working?</p> <p>He describes a potential life-threatening complication (this comes from personal knowledge) as something that is easily controlled with an injection.</p> <p><u>However</u>, the idea of being nauseated and of vomiting is dreadful.</p>
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Experience of treatment	<p>189. P: ... em, but I'd seen, you know some people got really</p> <p>190. jaundiced and they were really physically sick and eh ...</p> <p>191.</p> <p>192. CP: Like nausea and ...</p> <p>193.</p> <p>194. P: ... eh, yeah nausea ...</p> <p>195.</p> <p>196. CP: ... vomiting ...</p> <p>197.</p> <p>198. P: ... and vomiting, yes, sorry ... em, and I didn't really have that</p> <p>199. ... odd occasion but nothing, nothing major, you know I felt that</p> <p>200. my treatment was fairly smooth, eh wi no real problems</p> <p>201.</p> <p>202. CP: That's good</p> <p>203.</p> <p>204. P: And the same wi, the regime I'm on just now, eh I've just</p> <p>205. done my first cycle and em ... it's a slightly different set-up from</p> <p>206. the last time, but it's, eh most of the same eh chemo and it</p> <p>207. seems to be, it seems to be fine. I don't have any sort of</p> <p>208. reactions, any eh rashes as well, sometimes I think you get</p> <p>209. itchy and ... no, so I've been quite lucky that way</p> <p>210.</p> <p>211. CP: Mmm. Right. And ... what did you think when, how did</p> <p>212. you come, what happened when you came back? I mean did</p> <p>213. you have any symptoms again or ... ?</p> <p>214.</p> <p>215. P: Aw like eh recently here?</p> <p>216.</p> <p>217. CP: Yeah, yeah</p> <p>218.</p> <p>219. P: Y-e-a-h ... [sighs] ... it would be maybe about 6, 6 weeks ago,</p> <p>220. em I'd ... no, sorry maybe about 2 months ago I'd had a, a, a</p>	<p>Major side effects: nausea, vomiting – physically sick → These must be the horror stories he was referring to before.</p> <p>T</p> <p>Smooth chemotherapy</p> <p>Reactions = rashes (allergic reactions)</p>
Experience of treatment		

<p>Patient as expert.</p> <p>Patient as expert.</p> <p>Referring to previous experience.</p> <p>Fear of recurrence. Searching for clues.</p> <p>Patient as expert.</p> <p>Body as failure. Recurrence as second shock. Depression.</p> <p>The shock of relapse. Emotional distress from relapse. Coping strategy: cognitive processing Realisation of situation/relapse Fighting spirit purpose in life</p> <p>Practical problem-solving</p>	<p>221. cold ...</p> <p>222.</p> <p>223. CP: U-uhh</p> <p>224.</p> <p>225. P: ... and I knew because my immune system was still quite</p> <p>226. delicate that it was going to take, you know a lot longer than a</p> <p>227. couple of days to, to get better, but it went on for a good</p> <p>228. couple of weeks, em and I got treatment for it, you know from</p> <p>229. my local GP and it sort of cleared it up, but it didn't <i>quite</i> go</p> <p>230. away and then I was starting to get sort of boils coming up on</p> <p>231. my face and I was like this is sort of symptomatic of what</p> <p>232. happened the last time. Em, so I was up at the clinic, which I go</p> <p>233. eh once a month, you know the Day Clinic and they'd been</p> <p>234. taking my bloods, and I says you know I'm, I'm a bit wary here</p> <p>235. and they're going but your bloods are fine, you know there's,</p> <p>236. eh, your counts are low em, but there's, there's no, there's no</p> <p>237. leukaemia, there's no mutant cells, you're fine ... it's just it</p> <p>238. seems to be that you're marrow's not producing a lot, and I</p> <p>239. was like "OK". So the next time I went up they went well, can</p> <p>240. we take a, a bone marrow sample because your, your blood</p> <p>241. levels have dropped <i>again</i>, em, so they took the bone marrow</p> <p>242. and eh a couple of days later I got the news that the leukaemia</p> <p>243. was back in the marrow. Em ... well I actually had to come back</p> <p>244. here and, and speak to a doctor and em ... that was, that was a</p> <p>245. bit of a shock, that was a bit of a shock, yeah. I'm actually ... I'm</p> <p>246. on anti-depressants just now for a, a ... unrelated thing, and I</p> <p>247. haven't been very emotional for the last 6 months, you know</p> <p>248. I've just been sort of steady, I haven't been able to cry or</p> <p>249. anything like that, eh but when he told me that ... eh, I started</p> <p>250. crying and I, you know was quite weepy for eh 10 minutes. But</p> <p>251. then again I thought well ... I've beaten this before, it's maybe</p> <p>252. going to be a lot more difficult this time but, you know I'm</p>	<p>Patient as expert. He has a good understanding of how treatment for leukaemia works.</p> <p>T</p> <p>Patient as expert. Referring to previous experience.</p> <p>Looking for clues.</p> <p>Patient as expert.</p> <p>Sense of being disappointed with his body. His body failed him again.</p> <p>He is hesitating: he wasn't expecting this to happen again.</p> <p>Clinical depression. Relapse: had a very strong emotional impact. He hadn't cried for a while due to treatment (anti-dep) and yet when he heard the news about relapse he cried a lot.</p> <p>Being strong/fighting spirit. "back up" Realisation of things being more difficult / (...)</p>
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<p>Self-identity preservation.</p> <p>Changed mood.</p> <p>Changed viewpoint.</p> <p>Worrying about distant future.</p>	<p>285. depressants and not because you think things differently?</p> <p>286.</p> <p>287. P: Eh, oh that's, that's a difficult one, yes, yes ... em ...</p> <p>288.</p> <p>289. CP: Are you the same?</p> <p>290.</p> <p>291. P: Yes, I do think I'm the same person ...</p> <p>292.</p> <p>293. CP: M-mmm</p> <p>294.</p> <p>295. P: ... yeah, yeah. Em ... just not so emotional up and down, you</p> <p>296. know just a calmer person</p> <p>297.</p> <p>298. CP: Mmm. Do you think em, do you think you, you think</p> <p>299. things differently?</p> <p>300.</p> <p>301. P: Yeah, yeah I do. I do</p> <p>302.</p> <p>303. CP: In what way? Can you, I mean can you give me an</p> <p>304. example so I can understand what you mean... ?</p> <p>305.</p> <p>306. P: Em ... [slight pause], well I always ... I always sort of think</p> <p>307. about, you know looking forward to the future and, you know I,</p> <p>308. I must prepare myself for X amount of time, you know</p> <p>309. retirement or what, like that you know and ... "do I have a</p> <p>310. pension that's going to give me money when I retire?", you</p> <p>311. know 'cause I'm only ... what, 10, 20 years away from</p> <p>312. retirement, em ...</p> <p>313.</p> <p>314. CP: Only</p> <p>315.</p> <p>316. P: [laughs]</p>	<p>Self-identity preservation.</p> <p>G Calmer or apathic? Due to antidepressant.</p> <p>Plans for distant future and worries about trivial matters.</p>
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Loss of long-term future.	317.		
	318.	CP: [laughs]	
	319.		
	320.	P: Em ... you know so I, I don't, things like that used to always	
	321.	worry me, you know ...	
	322.		
Worrying about trivial matters,	323.	CP: Oh!	Loss of future.
	324.		
	325.	P: ... eh, "will I be able to pay my bills?" and, you know stuff like	
	326.	that ... but after I came out from the hospital after the first ...	
	327.		
Reprioritising 'Living for today'	328.	CP: The first time	T Loss of distant future leads to appreciation of present.
	329.		
	330.	P: ... I just went ... "sod it", you know "I, I, I don't care, I'm living	
	331.	for today", em, "I fancy that ... right I'm going to buy that"	
	332.	whereas I'd go "oooh that's a bit dear", you know ... so I	G 'Living for today'
	333.	became, I, I suppose a bit more impulsive ...	
	334.		
Living fuller life	335.	CP: M-mmm	
	336.		
	337.	P: ... and just, grab an opportunity ...	
	338.		Living life in full
Remission... given a second chance	339.	CP: Mmm	
	340.		
	341.	P: ... em, you know I did quite a lot in the year I was out, that I	
	342.	probably would never have done before, you know. Eh, I'd	
Impulsive behaviour	343.	book, I booked to go and see a, a, a pop band down in	
	344.	Edinburgh or Glasgow and I'd just go "well, get a hotel, get a	
	345.	ticket, get a train ticket ... ", whereas before it's like "can I find	
	346.	somebody to give me a cheap lift down?", and it was just like	
	347.	"nut ... just do it!", you know ... so yes in that way my attitude	
Living for today	348.	changed, I just wanted to take everything, you know tomorrow	Given a second chance. Chance to live. Worries about trivial things don't exist anymore.

<p>Remission... given a second chance Reprioritised value: enjoying life</p> <p>Looking for clues of relapse.</p> <p>Relapse as a 'body blow'.</p> <p>Emotional impact of relapse. Patient as expert.</p> <p>Realisation of leukaemia incurable. Living with leukaemia from</p>	<p>349. ... I'll deal with tomorrow – <i>tomorrow</i>, today's today, and that's</p> <p>350. basically what I've been doing for the last year</p> <p>351.</p> <p>352. CP: Are you happy with it?</p> <p>353.</p> <p>354. P: Yeah. Yeah. I mean oh there's lots of things in my life that</p> <p>355. would make me ever happier but, yeah, yeah ... and like I say</p> <p>356. that year I got out, em ... it's, it's been a really good year. Em,</p> <p>357. you know it's had its up and downs but generally I've just went</p> <p>358. "no, just ... I'm here to enjoy life now" and that's what I've</p> <p>359. done</p> <p>360.</p> <p>361. CP: That's really good. And what, when you said that your</p> <p>362. cried when you heard em, that it was back, the leukaemia was</p> <p>363. back ...</p> <p>364.</p> <p>365. P: M-mmm</p> <p>366.</p> <p>367. CP: ... what did you feel?</p> <p>368.</p> <p>369. P: [sighs] [sniffs] [slight pause] E-m ... well I, I had a nagging</p> <p>370. doubt that it was back, you know I had no proof that it was but</p> <p>371. I had a sort of nagging doubt. Em ... and when it was confirmed</p> <p>372. ... em ... [slight pause] ... it wasn't so much a shock because like</p> <p>373. I say I had a, a, an inkling but it's still quite a, a body blow, you</p> <p>374. know it's like ... "whoa!" ...</p> <p>375.</p> <p>376. CP: Mmm</p> <p>377.</p> <p>378. P: ... em ... yes, it's hard to say, it's hard to say, you know em ... I</p> <p>379. was obviously upset that it was back but I also knew that the</p> <p>380. chances of it coming back were always there, you know I, I am</p>	<p>G Living for today. Like he was given permission to live a fuller life. Realisation of mortality?</p> <p>T</p> <p>G What does he mean 'now'? Before he didn't enjoy life, he just lived with all trivial matters going by. He might refer to live for today. Realisation of his own mortality.</p> <p>T Nagging doubt/had no proof: searching for clues referring to previous experience. He is very hesitant at this point: efforts to make sense.</p> <p>Disappointment: his body let him down for a second time. D</p> <p>D Patient as expert</p>
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<p>now on. Senses of disappointment. Being appreciative of a second chance.</p> <p>Being hopeful.</p> <p>Patient as expert.</p> <p>Patient as expert.</p>	<p>381. quite aware that once it's treated it doesn't mean that it, it's</p> <p>382. going to go away forever. Em ... so again maybe a little bit</p> <p>383. resigned to the fact that, that it had come back, but then at the</p> <p>384. same time I was like well ... I've had an extra year that I might</p> <p>385. not have had so you know, it sort of tempered that</p> <p>386.</p> <p>387. CP: OK. And ... how many treatments are you going to have</p> <p>388. now?</p> <p>389.</p> <p>390. P: Em ... I think it's 5 cycles ...</p> <p>391.</p> <p>392. CP: 5</p> <p>393.</p> <p>394. P: ... of the, the chemo but this time once the chemo is finished</p> <p>395. and I hopefully go back into remission ...</p> <p>396.</p> <p>397. CP: M-mmm</p> <p>398.</p> <p>399. P: ... I need a full bone marrow transplant ...</p> <p>400.</p> <p>401. CP: M-mmm</p> <p>402.</p> <p>403. P: ... em, because what they've said is the sort of leukaemia</p> <p>404. killer in my immune system is switched off, so I need to get</p> <p>405. somebody else's immune system ...</p> <p>406.</p> <p>407. CP: M-mmm</p> <p>408.</p> <p>409. P: ... or, or else they said you know it's just going to keep</p> <p>410. coming back. Eh, so I don't know how long that's going to take</p> <p>411.</p> <p>412. CP: Mmm</p>	<p>Rationalising</p> <p>Realisation of no permanent cure.</p> <p>Disappointment with the body.</p> <p>T Being appreciative.</p> <p>G Given a second chance.</p> <p>There seems to be a lot of processing here. He is putting facts together. Efforts to understand.</p> <p>Patient as expert.</p> <p>Patient as expert.</p> <p>Patient as expert.</p>
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<p>Being realistic.</p>	<p>413. 414. P: I mean J said sometimes it can take years ... 415. 416. CP: Yeah 417. 418. P: ... to find a, a donor. Eh, I mean he explained it, they can 419. harvest my own stem cells, which will keep me going, <i>but</i> it 420. won't stop the leukaemia coming back, but it will keep, keep 421. me going so, it's just wait and see ... 422. 423. CP: Mmm 424. 425. P: ... eh I've got a brother and a sister who have both, well I 426. think my brother's coming in today or tomorrow to get tested 427. ... 428. 429. CP: Oh tested ... 430. 431. P: ... eh my sister came in last week to get tested so, we'll see, 432. but again I believe that's very, very rare for a sibling match as 433. well ... 434. 435. CP: It's hard, yeah ... 436. 437. P: ... but it's the best ... 438. 439. CP: ... but you can't ... 440. 441. P: ... match ... 442. 443. CP: ... yeah, but you cannot exclude the, the possibility of ... 444.</p>	<p>It looks like he is being cautiously hopeful.</p> <p>Good level of information. G (understanding) Coping style: watchful waiting. Well-informed.</p> <p>Being realistic.</p>
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<p>Focussing on current treatment.</p> <p>Impact of hospitalisation.</p> <p>Being hospitalised for leukaemia: being thrown into prison.</p> <p>Rationalising. Peer support.</p> <p>Support from nurses.</p> <p>Socialising in hospital.</p> <p>Practical issues when living in a hospital.</p>	<p>445. P: Oh ...</p> <p>446.</p> <p>447. CP: ... having one ...</p> <p>448.</p> <p>449. P: ... no, no no, no!</p> <p>450.</p> <p>451. CP: Yeah</p> <p>452.</p> <p>453. P: So em ... but I'm not actually thinking about that just now,</p> <p>454. that's in the future, I want to get through my, my chemo first</p> <p>455. and like I say hopefully go in to remission and then eh, it'll be a</p> <p>456. sort of milestone for me and then we can move on to the sort</p> <p>457. oh ... the bone marrow</p> <p>458.</p> <p>459. CP: M-mmm. I see. And how do you find life here, like in the</p> <p>460. ward?</p> <p>461.</p> <p>462. P: [slight pause] Difficult. It, well ... [sighs] ... I'm not the most</p> <p>463. em gregarious of people, you know I, I'm quite a loner ...</p> <p>464.</p> <p>465. CP: OK</p> <p>466.</p> <p>467. P: ... so sometimes when I'm thrown into, you know like a, a six-</p> <p>468. bed ward, eh a four-bed ward, I find it a bit ... you know it takes</p> <p>469. me a wee while to ... to, to get to know people, but because</p> <p>470. we're all in the same boat we usually all get you know quite</p> <p>471. friendly with each other, em and the nurses are fantastic here,</p> <p>472. a lot of the nurses were here when I was in last year as well</p> <p>473. which made a huge difference to have the ... "oh hello ..." and</p> <p>474. you, you know what I mean?</p> <p>475.</p> <p>476. CP: Yeah</p>	<p>T Focussing on present.</p> <p>G Patient as expert. Remission: a milestone.</p> <p>He is finding it hard to say how life in the ward was. Impact on everyday living. Personality characteristics: loner.</p> <p>D There is something here. A patient like with no will. The picture that comes in mind is a prisoner thrown into a cell with a number of strangers.</p> <p>T He is rationalising why he shouldn't find it so difficult to socialise with other patients: "we are on the same boat": They must find it difficult too. That is normal support from nurses.</p> <p>G Second time is more familiar environment. A sense of warmth/not a hostile environment.</p>
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<p>Rationalising.</p>	<p>477. 478. P: Actually know you, eh ... so that's good, the other thing is 479. because the ward's not really fit, for its use it gets really hot in 480. here and they don't have adequate ventilation. Em, that's 481. problem the, the biggest bugbear I think amongst patients here 482. is the actual heat that can build up here ... 483. 484. CP: Mmm 485. 486. P: ... but ... there's worse things in life [laughs] 487. 488. CP: You have this nice fan things ... 489. 490. P: Yeah, yeah 491. 492. CP: ... although.. 493. 494. P: ... eh the charity bought a load of them and they do work to 495. a certain ... to a certain extent, but if the sunshine is on that 496. windows the heat is just unbelievable ... 497. 498. CP: Intolerable 499. 500. P: ... how quick it builds up 501. 502. CP: Mmm 503. 504. P: ... but ... 505. 506. CP: Hmm 507. 508. P: We just have to get on with it ...</p>	<p>Practical difficulties in living in a hospital.</p> <p>Rationalising.</p>
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<p>Hospital as prison.</p> <p>Hospital as prison.</p> <p>Hospital as prison.</p>	<p>541. what you said?</p> <p>542.</p> <p>543. P: What ...</p> <p>544.</p> <p>545. CP: “A holiday in prison”</p> <p>546.</p> <p>547. P: Well [slight pause] ...</p> <p>548.</p> <p>549. CP: I'm sorry to ask you but ...</p> <p>550.</p> <p>551. P: No, no that's ...</p> <p>552.</p> <p>553. CP: ... I need to...</p> <p>554.</p> <p>555. P: ... that's, that's OK, it's, it's probably not the, the best, best</p> <p>556. turn of phrase, em ... it's just 'cause you know they're all</p> <p>557. institutionalised rooms, you know with the grey paint and ... I</p> <p>558. used to work off-shore in the early 70's and we always used to</p> <p>559. say that was like a prison but you're getting paid for it ...</p> <p>560.</p> <p>561. CP: [laughs]</p> <p>562.</p> <p>563. P: ... you know 'cause you're in a tight confined space and ...</p> <p>564. and ... I, I say jokingly ...</p> <p>565.</p> <p>566. CP: Yeah, yeah</p> <p>567.</p> <p>568. P: ... you know em, but that's, that's what I feel here, you know</p> <p>569. you're in little cells and eh, because ... because my eh counts</p> <p>570. are so low, I'm not really allowed to leave the ward so eh, you</p> <p>571. know it's like ... it's almost at the bars ... “can I get out for a</p> <p>572. walk ... ?”, and, do you know what I mean?</p>	<p>Two similar experiences:</p> <ol style="list-style-type: none"> 1. Working offshore: prison + money 2. Being treated at a hospital: prison + treatment <p>He explains why he feels like a prisoner.</p> <ul style="list-style-type: none"> ▪ Institutionalised ▪ Colour (grey) <p>*Being confined in a small place.</p> <p>D</p> <p>Previous experience.</p> <p>D</p> <p>He takes it back (like he regrets he said it). He is thinking of what my opinion will be of him.</p> <p>D</p> <p>The room is a cell: being a prisoner due to blood counts.</p> <p>A prisoner in the body.</p> <p>The body is weak (low counts), keeps the mind confined.</p>
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<p>Emotional impact of hospitalisation</p> <p>Leukaemia with no logic</p> <p>Leukaemia in disguise</p> <p>Impact of institutionalisation</p> <p>Doctors as gatekeepers/guards</p> <p>Impact of hospitalisation</p>	<p>573.</p> <p>574. CP: Yeah</p> <p>575.</p> <p>576. P: But all in fun, all in fun</p> <p>577.</p> <p>578. CP: Mmm</p> <p>579.</p> <p>580. P: And it's just, just something to keep me going. Stop me</p> <p>581. going stir crazy ...</p> <p>582.</p> <p>583. CP: Mmm</p> <p>584.</p> <p>585. P: ... 'cause I found that the first time I was in here, em some</p> <p>586. days if I, if I'd picked up a little infection that could may be ... 2,</p> <p>587. 3, 4 weeks before I'd be allowed to get a pass to get out, and I'd</p> <p>588. feel perfectly healthy, and it's like "sorry we can't let you out",</p> <p>589. and you're just sitting there going ... [sighs] ... you know getting</p> <p>590. really, really sort of frustrated. Em, but I, I, I ... I go with the</p> <p>591. doctor's orders, you know they're the experts, if they're saying</p> <p>592. it's not right for me to go out, that's fair enough, but at, at the</p> <p>593. same time, you know sometimes I was almost pulling my hair</p> <p>594. out if I had any, because I was ... "just get me out of here!"</p> <p>595. [laughs] ... even for an afternoon, you know ... but ...</p> <p>596.</p> <p>597. CP: Was, so the fact that you got yourself a computer, a small</p> <p>598. computer ...</p> <p>599.</p> <p>600. P: M-mmm</p> <p>601.</p> <p>602. CP: ... does it have to do with this, like is it your tactic of, you</p> <p>603. know fighting to being alone or, you know spending time or ...</p> <p>604. ?</p>	<p>He is trying to make this smaller than what it really is. Why? Is it a way to protect himself? Is it because of the fear of what impression is going to give me?</p> <p>Impact of institutionalisation: emotional, mental</p> <p>Illness impact (infectious) → prolonging institutionalising</p> <p>Illogical illness: feeling healthy still confined</p> <p>Prison ref. again</p> <p>Doctors as persons of authority/gatekeepers, guards</p> <p>Impact of institutionalisation</p> <p>Strong picture/metaphor: something usually women would say?</p>
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<p>Computer as a door to the world</p> <p>Impact of hospitalisation/ imprisonment</p>	<p>605.</p> <p>606. P: It's, it, well it occupies my mind ...</p> <p>607.</p> <p>608. CP: Mmm</p> <p>609.</p> <p>610. P: ... eh ...</p> <p>611.</p> <p>612. CP: Did you buy it because you would be in the hospital I mean?</p> <p>613.</p> <p>614.</p> <p>615. P: Yes</p> <p>616.</p> <p>617. CP: Or did you have it before?</p> <p>618.</p> <p>619. P: No. Well actually eh my brother leant me it ...</p> <p>620.</p> <p>621. CP: Mmm</p> <p>622.</p> <p>623. P: ... em, but I'm in the process, I, I will buy one for myself ...</p> <p>624.</p> <p>625. CP: Yeah</p> <p>626.</p> <p>627. P: ... but, yeah it was this ...</p> <p>628.</p> <p>629. CP: It was just because of ...</p> <p>630.</p> <p>631. P: ... eh specifically for being in here, yeah. Em ... because like</p> <p>632. is say it is an outlet to the world, em, but it also lets me listen</p> <p>633. to, you know the BBC and you know stuff like that, so I can</p> <p>634. keep on top oh things, 'cause that's another problem I find in</p> <p>635. here, is you lose days ... it's like what day is, is this Tuesday ...</p> <p>636. no it's, it's Thursday ...or is it Saturday? And ... you ... it, it's very</p>	<p>Computer as a window to the world.</p> <p>T</p> <p>D</p> <p>Impact of prison: losing track of time.</p>
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<p>Being depressive.</p> <p>Being depressive.</p> <p>Being depressive. General knowledge.</p> <p>Theory of being positive.</p> <p>Understanding of being positive. Self-suggestion.</p>	<p>637. easy to sort of lose track oh time. Eh, so that's another thing,</p> <p>638. you know I like to know what's going on and ...</p> <p>639.</p> <p>640. CP: Mmm, I see. And, now another thing ... one of you</p> <p>641. decisions it seems like well, from what I understand is that,</p> <p>642. you said when you heard that you had leukaemia or, I don't</p> <p>643. know how much time later you decided to be positive ...</p> <p>644.</p> <p>645. P: M-mmm</p> <p>646.</p> <p>647. CP: ... and em, would this be like, what, what sort of strategies</p> <p>648. did you use to be, I mean ...</p> <p>649.</p> <p>650. P: Well [sighs] ...</p> <p>651.</p> <p>652. CP: ... and, and do you think that's, this was what you would</p> <p>653. do before or was it something new that you had to decide to</p> <p>654. do?</p> <p>655.</p> <p>656. P: See I'm, I'm generally quite a depressive person ...</p> <p>657.</p> <p>658. CP: M-mmm</p> <p>659.</p> <p>660. P: ... quite sort oh low, em, so being positive and happy is not</p> <p>661. really my persona ...</p> <p>662.</p> <p>663. CP: Mmm</p> <p>664.</p> <p>665. P: ... though I, you know I am happy and ... but generally I'm</p> <p>666. quite a ... eh low person, but ... you know having, like I say, you</p> <p>667. know I, I, I read lots of things, watch lots of things and ... I</p> <p>668. believe that having a posi., positive attitude actually benefits</p>	<p>Being in time.</p> <p>Personality description: depressive, low</p> <p>He takes it back. Is he thinking what I will think of him? Coping style: conscious decision to be positive. Impact of positive attitude.</p>
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<p>Coping style: cognitive processing.</p> <p>Being positive as part of treatment.</p> <p>Belief system.</p> <p>Announcing diagnosis.</p> <p>Initial emotional impact of diagnosis.</p> <p>Protective relationship with mother.</p>	<p>669. the treatment. Em because if you're all depressed, I think that</p> <p>670. supresses your immune system to a certain extent, which is not</p> <p>671. going to help wi your treatment so I, I, I made a positive effort</p> <p>672. to say "right everything's going to be good" and if that hurts it</p> <p>673. doesn't matter because it's hurting because it's making me feel</p> <p>674. better and, you know I will, and it's really strange that eh, you</p> <p>675. know my friends are going: "you're smiling and you're, you're</p> <p>676. happy" about and that and it's like, well "I have to be", I have</p> <p>677. to be. I, I, I really feel that the positive attitude is an integral</p> <p>678. part of the treatment ... eh ...</p> <p>679.</p> <p>680. CP: Did you...</p> <p>681.</p> <p>682. P: ... eh, you know 'cause the mind's a wonderful thing. It does,</p> <p>683. you know it does a lot more than just think and ... it can, well I</p> <p>684. believe so anyway</p> <p>685.</p> <p>686. CP: M-mmm. That's good. Very good. And how about your</p> <p>687. friends, you said they're em, do you have lots of visitors and</p> <p>688. how did you announce them the fact that you ...</p> <p>689.</p> <p>690. P: [sighs] That was quite difficult</p> <p>691.</p> <p>692. CP: M-mmm</p> <p>693.</p> <p>694. P: Em ... [slight pause] ... the first person I told was my girlfriend</p> <p>695. at the time, we're not together anymore but em, em, just</p> <p>696. before I got the, the phone call saying "you have to go into</p> <p>697. hospital", em, I was in a bit of a panic and I was like "I have to</p> <p>698. speak to somebody ... I, I really need to speak to somebody", so</p> <p>699. I phoned her up and eh, I told her, you know "look I have to go</p> <p>700. in, it's cancerous of some description, I don't know but ...", eh,</p>	<p>He believes there's a link between emotional state and immune system.</p> <p>What is he referring to? Treatment, illness, being held in a hospital?</p> <p>He changed his attitude, he wasn't like that before.</p> <p>Being positive was the only choice.</p> <p>Positive attitude as part of the treatment.</p> <p>Belief system: mind and body.</p> <p>He was in shock. Panic: a strong emotion of extreme fear that followed the diagnosis.</p> <p>He chose to tell the girlfriend because he felt close to her and he</p>
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<p>Guilt. Impact of illness on the person.</p> <p>Check back.</p> <p>Being introverted.</p> <p>Breaking bad news to friends.</p> <p>Illness and social world.</p> <p>Breaking bad news to friends.</p>	<p>701. so I was quite happy telling her ... and I didn't really want to tell</p> <p>702. my mother because you know my, my dad had obviously died</p> <p>703. oh this, em ... and to be honest I'm not sure if I actually told my</p> <p>704. mother. I think my girlfriend might have, or my sister might</p> <p>705. have phoned her, em ... then my girlfriend had informed some</p> <p>706. of my closer friends and that kinda disseminated, em but there</p> <p>707. was a few people that, you know I had a, a phone when I came</p> <p>708. in here, a few folk texted me and ... "oh ... we were meant to</p> <p>709. meet you tonight", sort of thing and, I, I felt kinda guilty sort of</p> <p>710. ...</p> <p>711.</p> <p>712. CP: How?</p> <p>713.</p> <p>714. P: ... well ... nobody likes to, to be told bad news. Eh, and it was</p> <p>715. my bad news. I didn't want to spread my bad news to</p> <p>716. everybody, you know I didn't want people going ... "oooh ...",</p> <p>717. just because oh me, if you know what I mean? Eh, but</p> <p>718. inevitably you have to tell people, you know so I used to say</p> <p>719. "well ...", you know "I'm in hospital, I'm getting treatment ... eh</p> <p>720. for stuff ...", but not go into too great a detail, and then if they</p> <p>721. came in and visited then saw me, you know hooked up to</p> <p>722. something I would explain as, you know I've got leukaemia</p> <p>723. blah, blah, blah, blah, blah ... and you know rather than do it</p> <p>724. face-to-face with them ...</p> <p>725.</p> <p>726. CP: Yeah. Did you have experiences doing it through phone or</p> <p>727. texting and, did you have a bad experience I mean with doing</p> <p>728. it other ways?</p> <p>729.</p> <p>730. P: It's [sighs] ... I just don't like the ... you know when you're,</p> <p>731. when you're , when you're spreading bad news like that ... you</p> <p>732. know a text, a text's not really ... I, I don't think appropriate</p>	<p>was protecting his mother as well.</p> <p>Protecting. This: He means leukaemia. He doesn't use the word. He is quite hesitant in this point. Is it because of the difficult-emotional memories the interview brought up?</p> <p>Guilt why? Impact of illness in every day social life.</p> <p>Personality characteristic. He didn't want to scare people – introvert, low person. He doesn't want to be in the centre of attention.</p> <p>Ways of delivering the news of his diagnosis.</p> <p>He preferred personal communication.</p> <p>The use of the word 'spreading' sounds like contaminating. He values his friends and this is why he feels face-to-face communication is best to inform someone.</p>
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<p>Illness and social world.</p> <p>Support from friends.</p> <p>Illness and social world.</p> <p>Low self-esteem.</p> <p>Illness and social world.</p>	<p>733. way of sort of breaking the news to somebody. It might have</p> <p>734. been the case that that was the only way I could ...</p> <p>735.</p> <p>736. CP: You could do it...</p> <p>737.</p> <p>738. P: ... contact, but I wouldn't ... you know I'd say "oh hello bud,</p> <p>739. eh, I'm not feeling very well, how are you?", you know and I'd</p> <p>740. wait for a reply and maybe ...</p> <p>741.</p> <p>742. CP: [?] I see. Mmm. And how did you feel about, do you have</p> <p>743. like any, a weird or any reactions from your friends that, you</p> <p>744. know ... ?</p> <p>745.</p> <p>746. P: No. No, I mean they were all ... you know everybody was</p> <p>747. shocked. Eh, sad ... em but generally no, they were all, you</p> <p>748. know rallied round all ... you know we're with you all the way,</p> <p>749. let's, let's beat it sort oh thing, em ... no, no, not any weird</p> <p>750. ones. There was a couple oh people that I work with that were</p> <p>751. ... who would always ask after me, but wouldn't come into</p> <p>752. hospital, <i>which</i> I fully understand because personally I <i>really</i></p> <p>753. don't like visiting people in hospital myself, I, I, I feel ... I, I just</p> <p>754. don't like it. Em, but no, nobody, nobody had anything ...</p> <p>755. bizarre or weird that I can think of, reactions to it, no. No</p> <p>756. mostly, like I say sympathetic and sup., supporting</p> <p>757.</p> <p>758. CP: And how do you feel about that?</p> <p>759.</p> <p>760. P: About my, my friends?</p> <p>761.</p> <p>762. CP: Yeah</p> <p>763.</p> <p>764. P: Em ... I was <u>quite shocked</u> how many people sort of came out</p>	<p>However, he was told <u>by phone</u> and he phoned the girlfriend. So, what does this mean?</p> <p>Friends were shocked and supportive.</p>
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<p>Impact of support on self-esteem.</p> <p>Protective relationship with mother.</p>	<p>765. of the woodwork, you know I, I, I have a, a small, like I say I'm</p> <p>766. not a, a very gregarious person, I have a small sort of circle of</p> <p>767. friends and you know, I know a friend of a friend of a friend and</p> <p>768. then all of a sudden I was getting ... <i>not hundreds</i>, but you</p> <p>769. know dozens and dozens of people sending a card or sending a,</p> <p>770. their wishes and I was like ... "oh oh oh oh oh ... oh – <i>popular</i>"</p> <p>771. ... [laughs] ... which it, it did, it made me feel eh, really happy,</p> <p>772. you know ... people I hadn't have thought about in years would,</p> <p>773. would send a, a card in it's ... yeah. So it did ... that, that was a,</p> <p>774. a boost as well</p> <p>775.</p> <p>776. CP: Good. And ... let's go to your family now ...</p> <p>777.</p> <p>778. P: M-mmm</p> <p>779.</p> <p>780. CP: ... how did they learn em, your, how did your brother and</p> <p>781. sister learn for instance?</p> <p>782.</p> <p>783. P: The, the first time I got it?</p> <p>784.</p> <p>785. CP: Yeah, yeah, yeah</p> <p>786.</p> <p>787. P: Em ... I think girlfriend would have contacted eh my sister ...</p> <p>788.</p> <p>789. CP: M-mmm</p> <p>790.</p> <p>791. P: ... eh my brother works in the oil business in Nigeria so he's</p> <p>792. away a lot of the time, em so my sister would probably told him</p> <p>793. and my mum ...</p> <p>794.</p> <p>795. CP: Mmm</p> <p>796.</p>	<p>Why?</p> <p>Illness made him realise his friends.</p> <p>I am worth of having their sympathy.</p> <p>Knowing you have friends (by showing their sympathy) boosted his ego. He was worth of having that.</p>
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<p>Independent life as a choice.</p>	<p>797. P: ... em and this, this time when I came in ... em ... I didn't want 798. my mum to be too involved because she's, she's, she's getting 799. on a bit, you know. I mean she's not, she's not decrepit or 800. anything but you know she's ... I thought it would be quite a 801. strain on her to be, you know the next of kin and that, so I 802. made my sister next of kin and em she told my mum and told 803. my brother when he came home last week 804. 805. CP: Mmm. Does your relationship with them, well has your 806. relationship changed in any way? 807.</p>	<p>He adopted a protective attitude towards his mother. He doesn't want to burden her.</p> <p>Protective.</p> <p>Sister taking a more active role.</p>
<p>Independent life as a choice. Being a loner as a choice.</p>	<p>808. P: [slight pause] Not really, no. Em, I'm not particularly close to 809. my family. Eh, I don't really see a lot of my family, eh, you 810. know they live at one side of town, I live at the other side ... it's, 811. it's nothing nasty or anything, it's just ... you know I, I, I try to 812. lead a, quite an independent sort of life, whereas eh my 813. brother lives about 4 streets away my mum and my sister's sort 814. of in the next village, sort of thing so they, they still are quite a 815. close knit family. Em, you know I still ... speak to them 816. occasionally, send the birthday cards blah, blah, blah but I 817. really don't have a lot oh interaction eh with my own family... 818.</p>	<p>He is distancing himself from family: this he call independence.</p> <p>He is different: Brother/sister/mother → close knit famiy. He is outside of this 'net'.</p>
<p>Being a loner as a choice.</p>	<p>819. CP: Mmm 820.</p>	<p>He is a loner. It seems like they are strangers.</p>
<p>Distancing from family. Being a loner as a choice.</p>	<p>821. P: It, it's always been like that, you know since I, I left, 17 year 822. old or whatever ... 823. 824. CP: Mmm, m-mmm 825. 826. P: I mean I love my family ... 827. 828. CP: Yeah, no ...</p>	<p>The separation was done at an early stage.</p> <p>He is trying to justify what he said. Is he taking it back? Is he afraid of my judgement?</p>

<p>Loneliness in hospitalisation.</p> <p>Failed coping or negative coping strategies.</p> <p>Depression as personality characteristic.</p> <p>Depression.</p> <p>Drug abuse.</p>	<p>829.</p> <p>830. P: ... but it's just ... you know I, I ... I feel I ... [sighs] ... I don't</p> <p>831. have that much in common ...</p> <p>832.</p> <p>833. CP: Mmm, with them ...</p> <p>834.</p> <p>835. P: ... with, with them</p> <p>836.</p> <p>837. CP: ... mmm. Right. Em ... and you're, you're happy with, I</p> <p>838. mean em, with how this works out, I mean how em ... you</p> <p>839. don't feel like now that you're in the hospital you need to see</p> <p>840. them more and ... ?</p> <p>841.</p> <p>842. P: No</p> <p>843.</p> <p>844. CP: No.</p> <p>845.</p> <p>846. P: Not really no. I mean it's nice to have any visitors come in</p> <p>847. you know to break up the day but, no it, it hasn't really changed</p> <p>848.</p> <p>849. CP: Mmm. Alright. Em, we talked about your friends, em</p> <p>850. what I wanted to ask you is, I know it's, I guess a bit ... em,</p> <p>851. about how ... before, before you had leukaemia, how did you</p> <p>852. cope with hard situations, or difficult situations? What would</p> <p>853. you do?</p> <p>854.</p> <p>855. P: [sighs] <i>With difficult situations?</i> E-m ... I didn't cope very well</p> <p>856. actually. Em ...</p> <p>857.</p> <p>858. CP: What would you think to be good coping, I mean like ...</p> <p>859. what you mean like?</p> <p>860.</p>	<p>Now it's different: Not much in common.</p> <p>Why is he trying to separate himself from the family? At first, he called this independence; now, it's that they are different? Why is he saying this?</p> <p>'Any': Not specifically family. So, family isn't any different than other acquaintances?</p> <p>Hospital routine: Boredom – loneliness</p> <p>Need for having someone to break the routine.</p> <p>Failed coping strategies before leukaemia.</p>
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<p>Chronic fatigue.</p> <p>Difficulty accepting consequences of treatment.</p> <p>Doctor as a person of authority.</p> <p>Doctor as a person of authority.</p> <p>Depression – maniac disorder. Impact of mental disorder.</p>	<p>893. kicking walls and, you know punching walls and stuff outa</p> <p>894. frustration and sort of anger</p> <p>895.</p> <p>896. CP: Mmm, mmm. Do you think now that you're, you're</p> <p>897. copng better with things, well, especially with the biggest,</p> <p>898. which is your illness I suppose?</p> <p>899.</p> <p>900. P: Yeah, yeah. But I have to say it is the anti-depressants that</p> <p>901. have helped because ... after I, I, I came out last June ...</p> <p>902.</p> <p>903. CP: M-mmm</p> <p>904.</p> <p>905. P: ... and got the all-clear, you know I was coming every month</p> <p>906. eh to the Day Clinic, and everything you know was fine, but I</p> <p>907. just found, I, I just hadn't any strength still and they, you know</p> <p>908. they said well, you know it'll take a while for you to build up</p> <p>909. your strength 'cause you've been lying in a bed for 6 months</p> <p>910. and ... you know, you've had heavy treatment and I began to</p> <p>911. think there was something not quite right because, it got to the</p> <p>912. point I could walk for maybe 5-10 miles, quite, quite easily, just</p> <p>913. at a, a walking pace, <i>but</i>, if I was to run for 20 yards, or 20</p> <p>914. metres, you know for a bus, I would be absolutely devastated ...</p> <p>915. sweatin', gasping for air, and I was like ... "this can't be right",</p> <p>916. you know. So they had arranged to do various tests, you know</p> <p>917. with lung tests and heart tests and such like, em and then one</p> <p>918. day I saw, I think it was the Professor over there and he turned</p> <p>919. round and he said, "well ...", he says "after this amount of time</p> <p>920. eh, if you haven't had a health improvement eh, it's not going</p> <p>921. to get any better", he says ... "it seems quite obvious to me that</p> <p>922. eh, your hearts been damaged by the chemo", and him being a</p> <p>923. Professor I was like ... "OK I take that as ... as a given", and that</p> <p>924. put me into a <i>really</i>, so I, I think that was about October, that</p>	<p>*Maniac phase? Can this be a <u>bipolar</u> disease? NO Manic-depressive.</p> <p>Different coping style at the moment. Treatment helped with this mood.</p> <p>Chronic fatigue? D</p> <p>Denying – difficulty accepting. This is not me.</p> <p>Doctor as a person of authority. He accepted without asking any questions. 'That': Fatigue, the feeling of weakness.</p>
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<p>Relapse as a shot, a 'bang'.</p>	<p>957. CP: Or do you ... I mean ...</p> <p>958.</p> <p>959. P: ... and jog and ...</p> <p>960.</p> <p>961. CP: ... you walk outside ...</p> <p>962.</p> <p>963. P: Yeah</p> <p>964.</p> <p>965. CP: ... and you're by yourself?</p> <p>966.</p> <p>967. P: I mean I do a lot of that, yeah</p> <p>968.</p> <p>969. CP: Mmm</p> <p>970.</p> <p>971. P: Yeah</p> <p>972.</p> <p>973. CP: Mmm</p> <p>974.</p> <p>975. P: And I was actually ... I was actually getting to the point of</p> <p>976. getting my bike out of the attic and start cycling again ...</p> <p>977.</p> <p>978. CP: Yeah</p> <p>979.</p> <p>980. P: ... eh then, you know "bang" – <i>I'm back inside</i>, but. Eh, but I,</p> <p>981. no I was ... I, I've never been one for gym equipment and that,</p> <p>982. but. That might have been a mistake on my part, I don't know,</p> <p>983. I don't know</p> <p>984.</p> <p>985. CP: Oh well, some people like to go, some are, some like you</p> <p>986. apparently like the nature and like to go ...</p> <p>987.</p> <p>988. P: Yeah, yeah</p>	<p>Just when he was getting back to his old life.</p> <p>Disappointment.</p> <p>Shock. Is this a shot sound? The relapse as a shot to: plans, efforts to go back to previous self.</p>
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989.		
990.	CP: ... outside, so. There are two types of people regarding	
991.	exercise I guess, and of course there are, there are the ones	
992.	that don't like exercise at all ... but that's good to know. And	
993.	em ... right so ... have you em, how about now the second	
994.	time that, I mean well you, you are in three weeks, how, how,	
995.	how's your physical status now, so how, how you feel ...	
996.		
997.	P: I'm, I'm ...	
998.		
999.	CP: ... in terms of ... do you feel weak and tired and ...	
1000.		
1001.	P: Yes, yes	
1002.		
1003.	CP: ... all that?	
1004.		
1005.	P: Em, last Saturday I got a Day Pass ...	
1006.		
1007.	CP: M-mmm, meaning that you could go out for a day? ...	
1008.		
1009.	P: Go out ...	
1010.		
1011.	CP: ... like for some hours of the ...	
1012.		
1013.	P: Yes	
1014.		
1015.	CP: ... day?	
1016.		
1017.	P: Yes. Come back in, in the evening and ... I went a bit over the	
1018.	top, I must have walked about 3 or 4 miles and even today my	
1019.	muscles are still a bit ...	
1020.		

<p>Feeling a prisoner. Hospitalisation as imprisonment.</p> <p>Hospitalisation as imprisonment.</p> <p>Feeling a prisoner. Hospitalisation as imprisonment.</p>	<p>1053. how I felt .</p> <p>1054.</p> <p>1055. CP: So, so do you think that it would be beneficial for other</p> <p>1056. people like for, to have some, take some hours to re ...</p> <p>1057.</p> <p>1058. P: Definitely ...</p> <p>1059.</p> <p>1060. CP: ... yeah to ...</p> <p>1061.</p> <p>1062. P: ... definitely ...</p> <p>1063.</p> <p>1064. CP: ... go, mmm</p> <p>1065.</p> <p>1066. P: 'Cause some, sometimes you know because of the treatment</p> <p>1067. it can be a solid three weeks you're in a room, or you know</p> <p>1068. you're on the treatment and you can't go anywhere, and you</p> <p>1069. know even, like I say an afternoon can make so much of a</p> <p>1070. difference, well certainly to me ...</p> <p>1071.</p> <p>1072. CP: Yeah</p> <p>1073.</p> <p>1074. P: ... and I, I, I know speaking to, last year, you know</p> <p>1075. everybody's going "oooh ... I hope I get a pass, I hope I get a</p> <p>1076. weekend pass, hope I get a day pass", so it, it's, it's like a little</p> <p>1077. ...</p> <p>1078.</p> <p>1079. CP: Does this go back to what you said about eh, a holiday in</p> <p>1080. prison?</p> <p>1081.</p> <p>1082. P: Yeah, yeah I suppose it is, yeah, yeah</p> <p>1083.</p> <p>1084. CP: Mmm. So do you feel like you're, you have been</p>	<p>He really feels like a prisoner. Emotional boost of going home.</p> <p>Why staying in hospital is like prison? Strong feeling of confinement.</p>
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<p>Practical peer support.</p>	<p>1085. institutionalised being in the ward?</p> <p>1086.</p> <p>1087. P: At the moment – no, but last year, yeah, yeah, but as it went,</p> <p>1088. you know in the later stages yeah. You know 'cause eh, you get</p> <p>1089. woken at 6 for your bloods, you get your breakfast at 8, your</p> <p>1090. bed's changed by 9, the doctors are round between 10 and 11,</p> <p>1091. your dinner's at 12 ... you know what I mean it, it is all sort of</p> <p>1092. regimented ...</p> <p>1093.</p> <p>1094. CP: M-mmm, m-mmm</p> <p>1095.</p> <p>1096. P: So yeah, but like I say I, I am saying now a, a good humour ...</p> <p>1097.</p> <p>1098. CP: Yeah</p> <p>1099.</p> <p>1100. P: ... I ...</p> <p>1101.</p> <p>1102. CP: ... yeah, yeah, yeah. And in terms of support em, do you,</p> <p>1103. do you talk to people, do you, I mean what do you do to get</p> <p>1104. support from others?</p> <p>1105.</p> <p>1106. P: From other patients?</p> <p>1107.</p> <p>1108. CP: Other patients ... I don't know ... whatever you ...</p> <p>1109.</p> <p>1110. P: Well [coughs] ...</p> <p>1111.</p> <p>1112. CP: ... how do you get support ...</p> <p>1113.</p> <p>1114. P: ... yeah ...</p> <p>1115.</p> <p>1116. CP: ... besides the pills I mean?</p>	<p>The prison routine Institutionalisation in a hospital ward.</p> <p>He worries of me misinterpreting.</p>
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<p>Peer support.</p> <p>Patient as the expert.</p> <p>Support from nurses.</p> <p>Death as an experience.</p> <p>Comfort as emotional support.</p>	<p>1117.</p> <p>1118. P: Yeah, yeah ... em, not so much just now but, like I'm in a two</p> <p>1119. man room with a, an elderly gent and, you know never knew</p> <p>1120. him from Adam, but we get to know each other and eh, and we</p> <p>1121. support each other, you know he's, he's maybe not good on his</p> <p>1122. legs so I'll go and get this for him and ... stuff like that, so in that</p> <p>1123. way I think that's a kind of, you know supporting each other ...</p> <p>1124.</p> <p>1125. CP: Mmm</p> <p>1126.</p> <p>1127. P: ... but last year when I was in, there was a couple of really</p> <p>1128. nice eh people I met, <i>patients</i>, and em ... who'd had the same</p> <p>1129. AML as me and you know they went right through ... "oh this is</p> <p>1130. what happens", you know "expect that this might happen",</p> <p>1131. "you might have that set-back but don't worry because it'll go</p> <p>1132. and, and that helped a helluva lot. Because they, they've just</p> <p>1133. been through what I'm about to go through so I found that very</p> <p>1134. supportive</p> <p>1135.</p> <p>1136. CP: Good</p> <p>1137.</p> <p>1138. P: And the nurses, you know they're ... [sighs] ... you can almost</p> <p>1139. ask them for anything, you know they're always there. There</p> <p>1140. was a couple oh times last year eh when I was in one oh the</p> <p>1141. bigger wards and you know people were, were just dying next,</p> <p>1142. in the bed next to me which I found <i>really, really</i> upsetting, and</p> <p>1143. eh especially one time, I basically watched them, you know sort</p> <p>1144. of die ... and I was really sort of tearful and the nurse came,</p> <p>1145. pulled the curtains, sat and held my hand for like half an hour</p> <p>1146. 'til I was better and I, I mean you know ... you can't ask for</p> <p>1147. better than that ...</p> <p>1148.</p>	<p>Peer support.</p> <p>T</p> <p>Practical support.</p> <p>Peer support: telling him what to expect.</p> <p>Peer support.</p> <p>T</p> <p>Feeling connected with people who had the same illness.</p> <p>T</p> <p>Health care support (nurses).</p> <p>First contact with so dying.</p> <p>D</p> <p>T</p> <p>Experiencing death in the hospital.</p> <p>Comfort from nurses.</p> <p>Privacy.</p>
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<p>Fear of death.</p> <p>Emotional distress.</p> <p>Difficulty accepting death.</p> <p>Leukaemia as fatal illness.</p> <p>Difficulty accepting fatality.</p> <p>Stoicity.</p> <p>Sense of connectedness with strangers.</p> <p>Survivor's guilt.</p> <p>Survivor's guilt.</p>	<p>1149. CP: Mmm</p> <p>1150.</p> <p>1151. P: ... you know</p> <p>1152.</p> <p>1153. CP: What did you think at that day?</p> <p>1154.</p> <p>1155. P: Really upsetting. Really upsetting. Em ... there was one day</p> <p>1156. [coughs] ... there was one particular day when 3 people I knew,</p> <p>1157. 3 people I'd shared rooms with died all in the same day. Em,</p> <p>1158. and I just found it really, really upsetting, you know 'cause you,</p> <p>1159. you make these bonds with people, even, even though you,</p> <p>1160. you don't know them that well because you're stuck in, you do,</p> <p>1161. there is a sort of bond and yeah I found that really, really hard.</p> <p>1162. And then actually ... after I'd gone out and you know I was</p> <p>1163. going to the Day Clinic, when I first started I used to go to the</p> <p>1164. Day Clinic then I'd go on to the ward and you know leave a, a</p> <p>1165. box of sweets wi the nurses and have a, you know just a wee</p> <p>1166. chat and then I'd look on the board to see if there was any oh</p> <p>1167. the patients I knew and I'd maybe have, you know a quick, a</p> <p>1168. quick yap, which, you know was good. Em, but then it seemed</p> <p>1169. to be every month I went, it was like "oh is ... ?" <i>naw he's gone</i></p> <p>1170. ... you know, all these people were just going and I found that</p> <p>1171. quite upsetting, so I actually stopped going back on to the</p> <p>1172. ward, 'cause you know I, I just didn't want to find out that yet</p> <p>1173. another person I knew was no longer with us. But ... that's the</p> <p>1174. way of the world</p> <p>1175.</p> <p>1176. CP: That's true. And how, how did you feel when you heard</p> <p>1177. that someone wasn't there?</p> <p>1178.</p> <p>1179. P: [slight pause] Upset. Upset. Em ... [slight pause] ...</p> <p>1180.</p>	<p>The realisation of death</p> <p>D</p> <p>'Death overdose': he was exposed to dying very rapidly</p> <p>These people meant something to <u>me</u>/It could be me as well.</p> <p>Distress-emotional.</p> <p>He feels connected to these other patients, yet he doesn't want his family to know a lot about his condition – He excluded his family from his life, yet the death of roommates got him upset.</p> <p>Realisation of death/dying. Realising his own mortality.</p> <p>The ward becoming a home. Sense of keeping the links.</p> <p>He means 'dying'.</p> <p>He stopped going to protect himself. Difficulty accepting that leukaemia can be fatal.</p> <p>T</p> <p>Stoicity: that's life.</p> <p>G</p> <p>Emotional distress.</p>
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<p>Leukaemia as fatal illness.</p> <p>Emotional distress to fatality.</p> <p>Difficulty accepting the fatality of leukaemia.</p> <p>Blocking out the stressor as a coping strategy. Stoicity.</p>	<p>1181. CP: What did it mean to you?</p> <p>1182.</p> <p>1183. P: Well ... that's a hard one because you know I never really</p> <p>1184. knew the, the, the people that well but like I say because you're</p> <p>1185. stuck in you, you make these sort of bonds and I just felt</p> <p>1186. incredibly sad that they had made, eh, they hadn't made it, you</p> <p>1187. know and I had. Not that I was feeling guilty or anything but it</p> <p>1188. was just, it was like I wish they had made it, you know I wish</p> <p>1189. their treatment had worked. I think actually the worst one, in</p> <p>1190. fact the, the very last time I came here, eh the gent was still in</p> <p>1191. the ward and I went through to see him and he was all ...</p> <p>1192. happy, smiling and I was like "oh! – are you getting out?", and</p> <p>1193. he's like "yeah, yeah, yeah I'm, I'm going home eh today", I was</p> <p>1194. like "aw that's fantastic news", and he's like "yeah but I'm just</p> <p>1195. going home ..." and I was like ... "what do you mean?" and he's</p> <p>1196. like "my treatment's stopped", so basically he was going home</p> <p>1197. to die, and he, he, he was, you know he was so ... eh calm in</p> <p>1198. himself about it and he was, and I was like ... "aaaw ... ", you</p> <p>1199. know "what, what, what do you say to a man who's just told</p> <p>1200. you he's, he's away to go and die?", I found that really</p> <p>1201. upsetting, eh and that's, that was the, the reason I never came</p> <p>1202. back on to the ward. I think that was worse than actually</p> <p>1203. finding out somebody had died, it's actually a person telling</p> <p>1204. you "I'm just away to die". So, yeah I did, I found that really</p> <p>1205. upsetting but ...</p> <p>1206.</p> <p>1207. CP: Mmm</p> <p>1208.</p> <p>1209. P: ... you just, it's like I say you just have to get on with it,</p> <p>1210. people die all over the world</p> <p>1211.</p> <p>1212. CP: Maybe it's not about how well you know them or how, I</p>	<p>D, T</p> <p>Contradiction: These strangers stopped being strangers because they all shared the same illness: leukaemia.</p> <p>Sense of confinement.</p> <p>Emotional distress.</p> <p>They died and Ian still alive.</p> <p>Survivor's guilt.</p> <p>He takes it back.</p> <p>He warned other patients to survive.</p> <p>Emotional.</p> <p>He finds it hard to accept fatality of illness – coping style.</p> <p>Sounds emotional.</p> <p>He decided to protect himself from the sight of death: he stopped visiting the ward.</p> <p>D</p> <p>Difficulty being with others in a difficult situation.</p> <p>T</p> <p>Stoicity.</p> <p>Not sure if this is acceptance or blocking of the stressor.</p>
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1213.	mean these bonds you are saying, you're talking about are	
1214.	quite important, so it doesn't, really it doesn't mean that	
1215.	much if you don't know them like how they are in their	
1216.	everyday lives ...	
1217.		
1218.	P: M-mmm	
1219.		
1220.	CP: ... I mean you shared some experiences quite important	
1221.	and quite hard during ...	
1222.		
1223.	P: Well yeah, yeah we did ...	
1224.		
1225.	CP: ... your, your stay here so ...	
1226.		
1227.	P: Yeah, yeah	
1228.		
1229.	CP: That's really important, so it doesn't matter if you know	
1230.	them very well, if you knew who they were ...	
1231.		
1232.	P: M-mmm, yeah	
1233.		
1234.	CP: ... and ... it can be hard or, I, I shouldn't be saying that	
1235.	now, because it's all about you, but yes patients do come back	
1236.	mainly to see, well we, we had lots of patients coming back to	
1237.	see us and to be honest some of them, em, they would send	
1238.	their husbands or their wives and we were being told that	
1239.	they are around in the Day Unit, and we would got out to see	
1240.	them, because they, they wouldn't feel very comfortable	
1241.	coming back to the ward ...	
1242.		
1243.	P: Coming on the ward, yeah, yeah	
1244.		

<p>Focus on treatment.</p>	<p>1245. CP: Too many memories they would say</p> <p>1246.</p> <p>1247. P: Yeah, yeah I can understand that, yeah</p> <p>1248.</p> <p>1249. CP: It seems like quite the same ...</p> <p>1250.</p> <p>1251. P: Yeah, yeah</p> <p>1252.</p> <p>1253. CP: ... that you are discuss., ...</p> <p>1254.</p> <p>1255. P: I, I, I would ...</p> <p>1256.</p> <p>1257. CP: ... what, what you are saying yeah ...</p> <p>1258.</p> <p>1259. P: ... say that's eh very similar</p> <p>1260.</p> <p>1261. CP: However when you came back like for the second time,</p> <p>1262. did you have this feeling, like ... remembering the, because</p> <p>1263. you said that when you came back you saw many of the</p> <p>1264. nurses were the same ...</p> <p>1265.</p> <p>1266. P: M-mmm</p> <p>1267.</p> <p>1268. CP: ... like the first time and you felt quite familiar with ...</p> <p>1269.</p> <p>1270. P: Yes ...</p> <p>1271.</p> <p>1272. CP: ... the place ...</p> <p>1273.</p> <p>1274. P: ... yes</p> <p>1275.</p> <p>1276. CP: ... so ...</p>	<p>Returning to a familiar place.</p>
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<p>Coping strategy: buck up</p>	<p>1277. 1278. P: I found that really important 1279. 1280. CP: ... despite the fact that when you came back you had 1281. these experiences like of having people that haven't ... 1282. 1283. P: Well ... I think I must have just shut that off, you know it's 1284. like well "look you have to go back onto the ward, you must go 1285. on to the ward" so I must, I, I'm not actually aware oh that, eh 1286. now that you mention it, but I obviously have shut that part off 1287. ... 1288. 1289. CP: Mmm 1290. 1291. P: ... and you know ... 1292. . 1293. , CP: Like focussing on yourself ... 1294. . 1295. . P: Focus, yeah, yeah, focussing on myself, yeah ... 1296. . 1297. . CP: M-mmm, m-mmm 1298. . 1299. . P: ... yeah 1300. . 1301. . CP: And how did you say it ... bucking ... bucking ... ? 1302. . 1303. . P: Buck up 1304. . 1305. . CP: Buck up 1306. . 1307. . P: <i>Buck up!</i> 1308. .</p>	<p>Separating two different things: 1. My treatment is important 2. My fear of learning people die of leukaemia. T</p> <p>Coping style.</p>
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<p>Patient as expert.</p> <p>(*)</p> <p>Worrying about long-term future.</p>	<p>1309. . CP: Yes, mmm, mmm. Yeah, yeah. Really interesting. So em</p> <p>1310. . do you have, you, you, hopefully you will have some time off?</p> <p>1311. .</p> <p>1312. . P: Yeah I, at some point I will, yeah, I, I don't exactly know</p> <p>1313. . when. It, it can be really weird though, like I was told I wasn't</p> <p>1314. . going to get out for 3 weeks one day and then the very next</p> <p>1315. . day it was like "go away for the afternoon"</p> <p>1316. .</p> <p>1317. . CP: Ha</p> <p>1318. .</p> <p>1319. . P: You know ... "oh! OK, yeah!" ...</p> <p>1320. .</p> <p>1321. . CP: [laughs] Take the chance</p> <p>1322. .</p> <p>1323. . P: So it, you, you know it depends, you know they, they can</p> <p>1324. . spring it on you and, or they can say "right next Monday we'll</p> <p>1325. . give you two days", but then if I get a wee infection or</p> <p>1326. . something it's like ... "oooh I'm sorry", we have to go through a</p> <p>1327. . weeks' worth oh antibiotics before we can even think about</p> <p>1328. . putting you, and it's like well, you just have to live wi that ...</p> <p>1329. .</p> <p>1330. . CP: Mmm</p> <p>1331. .</p> <p>1332. . P: ... you know ... getting out is great, but it's not the be all and</p> <p>1333. . end all ...</p> <p>1334. .</p> <p>1335. . CP: M-mmm, m-mmm</p> <p>1336. .</p> <p>1337. . P: ... it's, it's, it's a treat, you know</p> <p>1338. .</p> <p>1339. . CP: M-mmm. And em the fact that, you said in the beginning</p> <p>1340. . that you're a person that likes planning to do things, and ...</p>	<p>T</p> <p>Patient as expert.</p> <p>Now he is acknowledging how important it is for him to go out, but take his treatment as well. [Is he taking it back? Or he knows that treatment is more important?]</p>
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	<p>1341. .</p> <p>1342. . P: Well I wouldn't say I'm ...</p> <p>1343. .</p> <p>1344. . CP: ... does it ...</p> <p>1345. .</p> <p>1346. . P: ... a “planner”, but I, I, I was always worried about the future,</p> <p>1347. . you know ...</p> <p>1348. .</p> <p>1349. . CP: Mmm, I mean does this thing that you have, it seems like</p> <p>1350. . you have quite an uncertainty about, you know when are you</p> <p>1351. . going to go out ...</p> <p>1352. .</p> <p>1353. . P: M-mmm</p> <p>1354. .</p> <p>1355. . CP: ... is it, is it right or, did I get it wrong?</p> <p>1356. .</p> <p>1357. . P: No. No that's right</p> <p>1358. .</p> <p>1359. . CP: I, I mean not quite right I guess ... em does it affect you the</p> <p>1360. . fact that you don't know when you will go out, or ... ?</p> <p>1361. .</p> <p>1362. . P: E-m ... [sighs] ... [slight pause] ... well to a certain extent it</p> <p>1363. . does, you know if, if you're building up ...</p> <p>1364. .</p> <p>1365. . [problem with recorder]</p> <p>1366. . [end of tape]</p>	
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Emergent Themes	Original Transcript	Exploratory Comments
<p>Home as sanctuary.</p> <p>Life in small things.</p> <p>Life in small things.</p> <p>Hospital taking away senses.</p> <p>Home as sanctuary.</p> <p>Fatigue impact.</p>	<p>1367. CP: Thanks very much for having time to see me ...</p> <p>1368.</p> <p>1369. P: Oh no it's a pleasure</p> <p>1370.</p> <p>1371. CP: ... for a second time. Em, so well first I'd like to ask you again, how was your last week, the week you were home?</p> <p>1372.</p> <p>1373.</p> <p>1374. P: It was fantastic. It was fantastic. Em, like I say ... just being out the, the hospital eh ... the, the one thing I really liked was actually having "weather"</p> <p>1375.</p> <p>1376.</p> <p>1377.</p> <p>1378. CP: Ooooh</p> <p>1379.</p> <p>1380. P: You know eh, one oh the days it was eh raining, a bit oh wind</p> <p>1381. – and I loved it ...</p> <p>1382.</p> <p>1383. CP: Oh</p> <p>1384.</p> <p>1385. P: ... you know just feeling the rain on my face, the wind and then smelling flowers and smelling the vegetation and ... <i>that</i></p> <p>1386. really sort oh perked me up, you know</p> <p>1387.</p> <p>1388.</p> <p>1389. CP: Mmm</p> <p>1390.</p> <p>1391. P: ... 'cause you're in a sort of sterile environment here eh so</p> <p>1392. that was good and then just the fact that I could go home,</p> <p>1393. relax, basically do what I want to do... Yeah. I mean I, I couldn't</p> <p>1394. do everything I wanted to do because obviously my strength is,</p>	<p>Importance – Impact of being able to go home between treatments.</p> <p>G</p> <p>Appreciating the little things in life.</p> <p>(maybe he things this because he feels so restrained when in the hospital)</p> <p>G</p> <p>Appreciating the little things in life.</p> <p>G</p> <p>Connection with nature as improving mood.</p> <p>Contradiction: Hospital → sterile; Home/outside → full of smells and senses</p> <p>D</p> <p>Restrictions placed by illness</p> <p>Fatigue as a distressful symptom</p>

<p>Sense of independence.</p> <p>Leukaemia restricting.</p> <p>Hospitalisation as imprisonment.</p> <p>Patient as expert.</p>	<p>1395. is all gone, you know so even walking to the shops was a bit of</p> <p>1396. a struggle but even that it, it was good just, 'cause I can go out</p> <p>1397. and do it for myself, eh, so yeah it was great, great</p> <p>1398.</p> <p>1399. CP: Really good</p> <p>1400.</p> <p>1401. P: Em I can't really think oh anything more, it was just ... you</p> <p>1402. know it's a, it's a ... [sighs] ... it's something you strive for here,</p> <p>1403. it's a little "goal" you go for you know, 'cause you, you know</p> <p>1404. you're going to be in here for months and months so any</p> <p>1405. chance oh even getting a day or a couple oh days is having a</p> <p>1406. goal that you're trying to, to, to go for, you know, so, yes I</p> <p>1407. can'nae wait for the next time [laughs]</p> <p>1408.</p> <p>1409. CP: That's good</p> <p>1410.</p> <p>1411. P: But that's going to be a wee while 'cause I've just started eh,</p> <p>1412. you know a new cycle eh yesterday so ...</p> <p>1413.</p> <p>1414. CP: O-K</p> <p>1415.</p> <p>1416. P: ... but, yeah</p> <p>1417.</p> <p>1418. CP: How long do these cycles take, normally?</p> <p>1419.</p> <p>1420. P: Eh ... these ... it's 5 days ...</p> <p>1421.</p> <p>1422. CP: M-mmm ...</p> <p>1423.</p> <p>1424. P: ... 5 days</p> <p>1425.</p> <p>1426. CP: ... I, I mean like ... the total...</p>	<p>T He wants to be independent. Losing his independence (one of the most important impacts of the illness) is something that really impacts on his emotional state.</p> <p>T Sense of confinement – being in prison.</p> <p>When receiving chemotherapy patients set small.</p> <p>D Goals: going home for a couple of days.</p> <p>G</p>
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<p>Patient as expert. 'Body blow'</p> <p>Body blow.</p> <p>Patient as expert. Hospital as prison.</p> <p>Efforts to understand illness.</p> <p>Efforts to understand.</p>	<p>1427.</p> <p>1428. P: ... of, of the actual chemo</p> <p>1429.</p> <p>1430. CP: ... in the total? Yeah, but the total duration of, you know</p> <p>1431. how much time you spend in the hospital</p> <p>1432.</p> <p>1433. P: Well it, it's all dependant on how my body reacts [m-mmm],</p> <p>1434. em ... I've got a horrible habit of picking up bugs so that slows</p> <p>1435. everything down, you know 'cause they have to treat that and,</p> <p>1436. you know my body obviously can't get any better, you know</p> <p>1437. the bloods counts can't get any better while it's still full oh</p> <p>1438. infection so that sort oh slows things down but ... [sighs]. What</p> <p>1439. was the last time I was in here was 5 months – <i>all in</i> before eh</p> <p>1440. the treatment was over, so I'm thinking it's going to be you</p> <p>1441. know round about ...</p> <p>1442.</p> <p>1443. CP: Again ...</p> <p>1444.</p> <p>1445. P: ... 6 months ... 5, 6 months [mmm] for the actual treatment,</p> <p>1446. before I go onto the next stage</p> <p>1447.</p> <p>1448. CP: Mmm. You said you have a bad habit ... why did you say</p> <p>1449. that?</p> <p>1450.</p> <p>1451. P: Yeah I know that's, that's, that doesn't really make sense</p> <p>1452. does it? Em ... it's not a habit, I, it's just one of these things I, I</p> <p>1453. just seem to pick up infections</p> <p>1454.</p> <p>1455. CP: Do you think it's <i>you</i> then?</p> <p>1456.</p> <p>1457. P: Mmmmmm ... I don't know, I, I really don't know. I wouldn't,</p> <p>1458. to be, to be honest, no it isn't me it's just ... [sighs], I don't know</p>	<p>Patient as expert.</p> <p>Patient as expert.</p> <p>D</p> <p>Sense of disappointment with his body.</p> <p>Disappointment with his body.</p> <p>Patient as expert.</p> <p>Stressing the confinement. Having to stay <u>in</u> the hospital for 5 months.</p> <p>He doesn't understand why this happens.</p> <p>He tries to find a reason.</p> <p>Being sarcastic.</p>
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Sarcasm as a coping style.	1459. – <i>luck?</i>	D He blames himself? T He takes it back: It's the environment – Rationalising. It's not <u>just</u> me.
Self-blame.	1460. 1461. CP: M-mmm 1462. 1463. P: You know I just have ... be at the wrong place at the wrong 1464. time or touch the wrong thing ... I, I, I don't know ... but yeah I, 1465. sorry I, I shouldn't be saying it's me, 'cause it isn't me it's, it's 1466. environment [mmm], it's environment eh, and it just so 1467. happens that I seem to catch them, but I'm sure other people 1468. get them as well 1469. 1470. CP: Well ... we, we, I only ask because you, you sounded like 1471. you blame yourself like ... 1472. 1473. P: Yeah and after I said it ... 1474. 1475. CP: ... you have like, this ... 1476. 1477. P: ... after I said it, it sounded like that and to be honest no, I 1478. don't blame myself ... 1479. 1480. CP: Oh OK 1481. 1482. P: It's, it's just the way [yeah], just the way I, I came out with it 1483. 1484. CP: Mmm 1485. 1486. P: No, no I don't blame myself for picking up these, that I'm, I'm 1487. attracting them or anything like that 1488. 1489. CP: [laughs] 1490.	
Efforts to understand illness.		
Rationalising as effort to understand.		He takes it back. He is rationalising.
		T He is not attracting infections: that would be insane. Yet, he cannot explain why they happen as he is taking all precautions.

<p>Leukaemia treatment trajectory.</p> <p>Efforts to understand treatment.</p> <p>Patient as expert.</p> <p>Adjusted health behaviour.</p>	<p>1491. P: Eh ...</p> <p>1492.</p> <p>1493. CP: Yeah. Mmm</p> <p>1494.</p> <p>1495. P: But it's, it's one of these things, you know I'll, I'll get an</p> <p>1496. infection and it just slows everything down but, whereas I know</p> <p>1497. some people will go through their therapy, they'll be fine and</p> <p>1498. they can get out within maybe a week or two weeks of after</p> <p>1499. finishing their treatment [mmm], where it seems to be that I'm</p> <p>1500. maybe 2, 3 weeks [mmm], eh before I'll, I'll get eh a break, but</p> <p>1501. ... that's just one oh these things</p> <p>1502.</p> <p>1503. CP: Mmm, but do you think it's something that you do that</p> <p>1504. has to do with this?</p> <p>1505.</p> <p>1506. P: N-n-n-n-o ... I don't think so, no, because I, I am quite</p> <p>1507. fastidious about people touching me ...</p> <p>1508.</p> <p>1509. CP: Oh</p> <p>1510.</p> <p>1511. P: ... you know like with my, my friends and family [mmm], you</p> <p>1512. know it's like "don't shake my hand, don't give me a hug", or</p> <p>1513. anything like that – <i>just in case</i> [m-mmm], and you know if I'm</p> <p>1514. going to the toilet or anything I'm always using the ... the</p> <p>1515. alcohol rubs so you know I, I take it quite serious, eh about sort</p> <p>1516. oh trying to keep myself as eh clean or whatever, you know</p> <p>1517. "sanitised" [laughs] ...</p> <p>1518.</p> <p>1519. CP: Yeah. OK ... sensible. Em ... you said ... some of the things</p> <p>1520. you said during the first interview, well one that actually</p> <p>1521. struck, struck me ...</p> <p>1522.</p>	<p>He compares himself to others. Infections slow things down. With other types of illness?</p> <p>It takes longer for <u>me</u>. Is he blaming his body? He has to deal with infections as part of his illness. In a way it seems like the impact is bigger as it <u>slows</u> things down to this prison.</p> <p>Patient as expert.</p> <p>Being very cautious: That is why he cannot understand why he gets infections.</p>
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<p>Understanding. Coping style – belief system: body and mind</p>	<p>1523. P: M-mmm 1524. 1525. CP: ... em was the fact that you had to have a positive attitude 1526. 1527. P: Yes 1528. 1529. CP: ... you said “I'm going to buck-up ... 1530. 1531. P: M-mmm 1532. 1533. CP: ... and be positive and face this” 1534. 1535. P: Yeah 1536. 1537. 6 CP: Can you tell me like a tactic that you're using ... 1538. 1539. P: [sighs] 1540. 1541. CP: ... that you haven't been using I mean before because you 1542. said you weren't very optimistic and ... 1543. 1544. P: M-mmm I've always ... 1545. 1546. CP: ... like a very ... 1547. 1548. P: ... I've always been a sort of depressive [mmm] pessimistic 1549. person, I think it's an Aberdonian trait to be quite honest, living 1550. in a grey sort of city. But em ... I mean I, I've read up about 1551. things like this before [m-mmm], eh, you know I've got a thirst 1552. for knowledge, even if it doesn't directly affect me or anything 1553. and you know one of the things I have been aware of is having 1554. a positive attitude <i>can</i>, you know using your brain to actually</p>	<p>D Personality characteristics: depressive He offers a geographical reason for this (*)</p> <p>General pool of knowledge.</p> <p>Link between brain and body: power of mind. T This is something found in eastern philosophies.</p>
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<p>Coping style: self-suggestion.</p>	<p>1555. control, or maybe not control, but to help change eh the way 1556. your body works [m-mmm] em and I thought, yeah a positive 1557. attitude just ... [sighs] ... is it having a “faith”? - I don't know, 1558. 'cause I'm not a religious person but just believing that I am 1559. going to get better, therefore I will get better 1560. 1561. CP: Mmm</p>	<p>Believing in self-healing. Coping style.</p>
<p>Cognitive coping.</p>	<p>1562. 1563. P: Em which is, like I say because I'm such a pessimist it was 1564. quite hard but I realised once I was in here I needed to do that, 1565. 'cause I, if I was going to stay here and just go ... mump and 1566. moan about ... “oh I'm going to die ...”, or “this is not going to 1567. work ...”, it would have a negative effect on the treatment I 1568. believe [mmm], so that's why I'm just, I try to be you know 1569. happy and, if anything goes wrong, <i>well</i>, it'll get better the next 1570. time round, you, you know what I mean? 1571.</p>	<p>D Despite him having a different coping style. He <u>decided</u> to be positive. T</p>
<p>Being positive, hopeful.</p>	<p>1572. CP: Mmm 1573. 1574. P: Eh ... I, I'd say there's no, no real method, methodology 1575. about it, it's just like, just, just try and be positive about 1576. everything ... not look on the, the dark side, always look on the 1577. sort oh ... 1578.</p>	<p>Change in coping and personality characteristic.</p>
<p>Coping style: being positive.</p>	<p>1579. CP: Bright side 1580. 1581. P: ... the bright side oh things, yeah 1582.</p>	<p>Being positive and optimistic. G</p>
<p>Changed belief.</p>	<p>1583. CP: Mmm. Mmm 1584. 1585. P: You know 'cause out of every negative, you can get a positive 1586.</p>	<p>Looking on the bright side.</p> <p>Changed attitude → changed self.</p>

<p>Being positive.</p> <p>Having a purpose in life.</p> <p>Purpose in life.</p>	<p>1587. CP: Mmm</p> <p>1588.</p> <p>1589. P: That's what I'm trying to do anyway, and so far so good, you</p> <p>1590. know eh my treatment this time seems to be working well, em,</p> <p>1591. so I just keep at it, just try and keep a smiley face ... or more a</p> <p>1592. smiley mind, you know, just keep thinking "I will get better ...</p> <p>1593. I've got to many things to do in my life ... " ...</p> <p>1594.</p> <p>1595. CP: Like?</p> <p>1596.</p> <p>1597. P: [sighs] I haven't done much in my life you know ... I haven't</p> <p>1598. been a., I've been abroad once in my life you know, I'd like to</p> <p>1599. go abroad, em, see a bit oh life, em ... I play in a band, I want to</p> <p>1600. record more music, I want to play live a lot more [sounds</p> <p>1601. emotional], em I love nature, I want to go walking in the</p> <p>1602. woods, I'm a hill-walker, <i>or I was a hill-walker</i>, there's still so</p> <p>1603. many hills in Scotland that I need to climb ... you know, so I've</p> <p>1604. got all that in front oh me, it's like yes that's, I'm going to do</p> <p>1605. these things, you know</p> <p>1606.</p> <p>1607. CP: Oh right. These are all activities like, can you tell me</p> <p>1608. something more personal if you feel comfortable?</p> <p>1609.</p> <p>1610. P: About ... a, a ...</p> <p>1611.</p> <p>1612. CP: I don't know ... get married?</p> <p>1613.</p> <p>1614. P: Like relationships?</p> <p>1615.</p> <p>1616. CP: Yes</p> <p>1617.</p> <p>1618. P: That's ... that's a bit more problematic. Em 'cause I've been</p>	<p>Being positive.</p> <p>T</p> <p>Having a purpose to live.</p> <p>G</p> <p>Wanting a second (or third) chance.</p> <p>Plans for the future.</p> <p>G</p>
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<p>Protecting the self.</p> <p>Focussing on getting physically better.</p> <p>Leukaemia fatal.</p> <p>Realising own mortality.</p>	<p>1619. thinking about that recently [m-mmm], em I was in a fairly</p> <p>1620. long-term relationship up until a couple oh months ago [mmm],</p> <p>1621. em ... and it finished but very amicable I'm still very, very</p> <p>1622. friendly eh with the person, em ... <i>but</i> I can't see us ever having</p> <p>1623. an intimate relationship again ...</p> <p>1624.</p> <p>1625. CP: Going back</p> <p>1626.</p> <p>1627. P: ... we'll, we'll always be ... you know good friends [mmm] but</p> <p>1628. I, I can't see us eh sort of getting back together, and ... to be</p> <p>1629. honest I, I don't know how ... I'm a bit wary about getting into a</p> <p>1630. relationship with anybody just now because I don't think it'd be</p> <p>1631. actually fair on them ...</p> <p>1632.</p> <p>1633. CP: How come?</p> <p>1634.</p> <p>1635. P: ... with my condition at the moment ... maybe in the future if</p> <p>1636. I go into total remission, get my bone marrow and you know I</p> <p>1637. get the "all clear", that might be different, but at the moment I</p> <p>1638. don't think it's really fair to get involved wi somebody if I'm in</p> <p>1639. the condition I'm in ... if you know what I mean</p> <p>1640.</p> <p>1641. CP: I don't, you can tell me more</p> <p>1642.</p> <p>1643. P: Well it's ... I think I'm ju., I would be taking too much baggage</p> <p>1644. along with me, you know the fact is em ... it's not certain that</p> <p>1645. the treatment will work [m-mmm], you know and I don't want</p> <p>1646. to get involved with somebody and then tell them "oh I've got</p> <p>1647. X amount oh months to g., to live", you know I don't think</p> <p>1648. that's fair on a person, to get really involved with someone and</p> <p>1649. then say "oh, by the way", you know "I'm going to pop my</p> <p>1650. clogs" eh, so ... that's, that's how I feel at the moment ... that ...</p>	<p>Alienating from others.</p> <p>He doesn't want to be too involved with. So: is he protecting the partner or himself?</p> <p>T</p> <p>T Realising that death could happen.</p> <p>Realising his own mortality.</p> <p>Sarcasm.</p>
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<p>Protection of the self in loneliness.</p>	<p>1651. [mmm], em ... I, I don't know how else to put it. You know I'd 1652. like to be in a relationship with somebody ... 1653. 1654. CP: So you're not like saying, OK I'm not looking for, at the 1655. moment, you're shutting all the doors and windows and 1656. whatever ... 1657. 1658. P: Well I wouldn't say I'm shutting ... 1659. 1660. CP: Everything ... 1661. 1662. P: ... everything, everything, everything out, you know I still like 1663. to have em ... even sort oh ... a plutonic [means platonic] ... 1664. 1665. CP: Yeah ... 1666. 1667. P: ... relationship ... 1668. 1669. CP: ... companionship ... 1670. 1671. P: ... with somebody, you know just a ... 1672. 1673. CP: ... yeah, yeah ... 1674. 1675. P: ... friends and that but [mmm], at this moment in time I 1676. wouldn't want to get heavy, heavy ... "heavily" involved 1677. [mmm, mmm] with a person for the reasons I've just said 1678. [mmm], 'cause I, I just, I, I really don't think that would be fair 1679. ... but I might change ... I might just bump into somebody and 1680. [snaps fingers] ... you, you never can tell you know 1681. 1682. CP: No you can't</p>	<p>It's like he is focussing on himself at the physical sort of level and letting the emotional part out of the story. Is he becoming more introvert?</p>
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<p>Belief system: mind-body.</p>	<p>1683. 1684. P: ... but eh that, that's the way I feel just now [mmm], that's 1685. the way I feel just now 1686. 1687. CP: Mmm. Right and you said lots of activities that you want, 1688. you know to endeavour with ... 1689. 1690. P: M-mmm 1691. 1692. CP: ... em ... one of the things you said is you actually ... did 1693. mention this em ... I have to take you back, I'm sorry ... 1694. 1695. P: Yeah, yeah 1696. 1697. CP: ... I have to take you back to ... you, you said, you did 1698. mention it now, you said about the mind ... 1699. 1700. P: M-mmm 1701. 1702. CP: ... you said the mind was a won., is a wonderful thing ... 1703. 1704. P: Oh yeah 1705. 1706. CP: ... it does ... 1707. 1708. P: ... yeah 1709. 1710. CP: ... more things than just think [m-mmm] – so like? What 1711. kind of things, I mean how do you think, I mean this goes back 1712. to the first thing we discussed about em you thinking you 1713. know the positive, having a positive attitude and all that ... 1714.</p>	
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<p>Coping strategy.</p> <p>Self-suggestion.</p> <p>Power of mind.</p>	<p>1715. P: It's, I mean [coughs] I'm not the most educated of people but</p> <p>1716. I've always been fascinated by how the mind ... and the brain</p> <p>1717. are connected, 'cause the mind, it's not actually something</p> <p>1718. physical [m-mmm], but it's part of the brain which is physical,</p> <p>1719. it, it's just something that's fascinated me for years ...</p> <p>1720.</p> <p>1721. CP: M-mmm</p> <p>1722.</p> <p>1723. P: ... and the fact that, you know we only use, <i>what is it a 10th?</i>,</p> <p>1724. of eh the actual brain eh for all our functions, so there's all this</p> <p>1725. potential eh in the mind to do things. Eh I mean I could get</p> <p>1726. quite esoteric about telekinesis and all this sort of ... which I'm</p> <p>1727. quite sceptical about but I, I do feel that the mind has got a lot</p> <p>1728. more potential than we're actually, use just now</p> <p>1729.</p> <p>1730. CP: Mmm and how is this, I mean how is this relevant with</p> <p>1731. how you see leukaemia or how ...</p> <p>1732.</p> <p>1733. P: Well [sighs] ... I don't know. E-m [sighs] it's, aw ... I find it</p> <p>1734. quite hard to explain ... I, I just, like I say because I've, I've read</p> <p>1735. up and [mmm], you know about people that eh ... well actually</p> <p>1736. people wi like tumours and stuff that have been told they're</p> <p>1737. terminal and you know they've used eh different like</p> <p>1738. medication or different sort oh techniques [m-mmm], non-</p> <p>1739. physical techniques [m-mmm], and you know they've actually</p> <p>1740. shrunk tumours [m-mmm] and eh actually totally lost tumours</p> <p>1741. you know without taking any medication, I mean a lot oh this is</p> <p>1742. anecdotal but I'm, I'm quite prepared to believe that you know</p> <p>1743. these things are possible with your mind</p> <p>1744.</p> <p>1745. CP: Mmm. So then would you think that you would like to do</p> <p>1746. something different, well, apart from your chemotherapy</p>	<p>Alternative treatment (mind) and how it works.</p> <p>T Believing in the power of mind.</p>
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<p>Coping styles.</p>	<p>1747. treatment, would you be interested in you know doing 1748. something with this sort of treatment, like guided imagery ... 1749. is this? 1750. 1751. P: Yeah ... yeah ... 1752. 1753. CP: something like... 1754. 1755. P: ... I mean I, I've done bits of meditation and yoga in the past 1756. [m-mmm], em and ... 1757. 1758. CP: In, in the past, you mean before leukaemia? 1759. 1760. P: Yeah, yeah [m-mmm, mmm]. Em ... and yeah I'd be 1761. interested, I, I have done a bit of meditation, I find that quite 1762. difficult 'cause my head's always birling , yes [mmm], you know 1763. it's always [yeah] on the go, but em ... I actually use eh Ti., 1764. Tibetan Singing Bowls, I don't know if you're aware of these? 1765. 1766. CP: No I, I don't think I have ... 1767. 1768. P: It's em ... 1769. 1770. CP: Are these the two, two balls that have something in them 1771. and when you keep them they ... 1772. 1773. P: No 1774. 1775. CP: ... no, not that... 1776. 1777. P: ... I think you're thinking oh the Chinese ... 1778.</p>	
<p>Coping style.</p>		<p>Coping style: alternative → music/meditation</p>

<p>Coping style: relaxation techniques.</p>	<p>1779. CP: Must be ... 1780. 1781. P: ... balls ... 1782. 1783. CP: ... yeah, must be 1784. 1785. P: These are ... to all intents and purposes they, they just look 1786. like a brass bowl [u-uhh] but they actually, you know when you, 1787. you put your finger round a [u-uhh], a wine glass [yeah] and 1788. you get that sort of ... 1789. 1790. CP: The, there's ... 1791. 1792. P: ... noise ... 1793. 1794. CP: ... there's a sound, yeah 1795. 1796. P: ... it's the same wi these bowls, if you rub the edge of it [m- 1797. mmm] and it brings up, well one of my bowls has got about 4 1798. or 5 different tones, and again it's down to ... I feel using your 1799. mind and you know concentrating on it and you can lift up 1800. certain notes, drop them down and ... sort oh 10 minutes of 1801. doing that really sort of concentrating on it and it just totally 1802. empties the mind, totally relaxed and ... I find that really good 1803. [mmm], and again that goes back to I'm sure it's, it's maybe not 1804. but I'm sure it's the mind, it's directing the hand to actually get 1805. the tones to change and go up and down [mmm, mmm], 1806. maybe not, maybe it's just all rubbish [laughs] ... 1807. 1808. CP: Well if you find it helpful that's ... 1809. 1810. P: ... but I do, I've got a couple oh these bowls and, yeah. Like</p>	<p>Relaxation technique. T</p>
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	<p>1811. eh ... aye before the leukaemia and that when, when I was 1812. getting really stressed out by things and eh like I say I would 1813. just sit in a room and play wi these for half an hour and it 1814. would just chill me out and put a better perspective on life, you 1815. know [mmm], get rid oh the sort oh negative thoughts and get 1816. more positive thoughts 1817. 1818. CP: Mmm, and have you been using it like now during ... ? 1819. 1820. P: Not in here, because ... 1821. 1822. CP: Is it very loud? It can be annoying ... 1823. 1824. P: It ... 1825. 1826. CP: ... to other people 1827. 1828. P: ... I, I think it would be annoying to other people ... 1829. 1830. CP: OK 1831. 1832. P: ... because some oh the tones are not ... are not the most eh 1833. ... what's the word ... pleasant to listen to, some of them are 1834. quite harsh ... 1835. 1836. CP: Mmm, mmm 1837. 1838. P: ... and like I say it takes a lot of concentration to actually 1839. [mmm], get it right and stuff, but it is, I do use it at home 1840. [mmm], I do use it at home 1841. 1842. CP: So you did use it now, this week you were home</p>	<p>T</p>
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<p>Coping technique: relaxation through music.</p>	<p>1843. 1844. P: I did, yes, yes 1845. 1846. CP: That's really interesting... 1847. 1848. P: But part ... another thing I do is em I play music [m-mmm] 1849. and eh I do lots oh, well it's not really music, it's just drones ... 1850. 1851. CP: What does it do? 1852. 1853. P: ... you know just like a single tone [m-mmm] but it'll just 1854. subtly change [m-mmm] over a period of time [m-mmm], you 1855. know I'll, I'll do pieces that are like 15, 20 minutes long with 1856. just barely one tone on it [m-mmm] and again I find that very 1857. good to, to relax to as well [mmm], eh and I, I buy quite a lot of 1858. music which is based like that, just long sort of non-musical, 1859. just sort of tones and stuff and I find that very relaxing 1860. 1861. CP: Mmm. What kind of instrument do you play? 1862. 1863. P: All sorts 1864. 1865. CP: Wow! 1866. 1867. P: I've got a ... I, I, I'm very embarrassed to say I'm a musician 1868. 'cause I can't play a single note [u-uhh], so I just make noises as 1869. such, but I've got all sorts of things, I've got eh keyboards, 1870. children's toys [mmm], you know squeaky toys and stuff, eh 1871. guitars, eh I've got zithers, violins, penny whistles ... just 1872. anything you know that makes a noise [m-mmm], em ... and 1873. then I'll mix them all up on my computer and sort oh [oh right] 1874. play about with them and stuff [mmm], re-process them</p>	<p>Music as a relaxation technique.</p>
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<p>Leukaemia helped in living a fuller life.</p>	<p>1875. 1876. CP: And is it something you had all the time, or did you take it more, or did you apprehend it more, or you were interested in it after the illness? 1877. 1878. 1879. 1880. P: Oh no this is, ever since ... 1881. 1882. CP: [It's part of you?] 1883. 1884. P: ... I've been a, ever since I've been a, oh a young teenager, 1885. I've, I've always been into listening to music and I was always ... 1886. one my greatest things was to actually be a musician and get 1887. on stage and you know the sort oh rock and roll sort oh thing ... 1888. 1889. CP: Oh right 1890. 1891. P: ... em which, at the age of 43 I finally got on stage, which I 1892. never thought I would ever do ... 1893. 1894. CP: Wow 1895. 1896. P: ... played in front of audiences and, 'cause I, I am quite a shy 1897. person, you know and it was, it was really hard to be convinced 1898. to sort oh join this band and get up and do it but, once I did it - 1899. <i>I loved it</i>, loved it ... 1900. 1901. CP: Mmm... good.. 1902. 1903. P: ... so that's another thing I, I want, well I, I did mention that is 1904. get back up on stage and play more music, well make more 1905. noises [laughs] ... 1906.</p>	<p>Having this second chance in life. G</p>
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<p>Purpose in life.</p>	<p>1907. CP: [laughs] Aw, I wish you will... mmm</p> <p>1908.</p> <p>1909. P: But eh, I mean the feeling, you know the ... the rush oh</p> <p>1910. adrenaline and, oh it's, it's great, I love it, love it. Still get</p> <p>1911. frightened beforehand [yeah] but once you're up there and</p> <p>1912. you're doing it it's, it's great</p> <p>1913.</p> <p>1914. CP: I think everybody, eh all these big stars, well big stars,</p> <p>1915. actors whatever, they do have this stage fright is it called...</p> <p>1916.</p> <p>1917. P: M-mmm, m-mmm</p> <p>1918.</p> <p>1919. CP: ... like that, so, so it's normal</p> <p>1920.</p> <p>1921. P: Oh yeah, yeah, yeah. But eh ...</p> <p>1922.</p> <p>1923. CP: Wow</p> <p>1924.</p> <p>1925. P: ... that's just one oh the things you know it's something to</p> <p>1926. look forward to and ...</p> <p>1927.</p> <p>1928. CP: Doing good...</p> <p>1929.</p> <p>1930. P: ... making more records and stuff, 'cause eh I'm actually, well</p> <p>1931. last time I was in here I'd actually taken in a bag oh electronics</p> <p>1932. so I could do stuff on the computer [m-mmm], that got thrown</p> <p>1933. out for the week the next day so it was like "oh", eh but I'll get</p> <p>1934. them back up and you know maybe start doing bits and pieces.</p> <p>1935. 'Cause with electronics I can just do it with the headphones and</p> <p>1936. it's not going to annoy [mmm], eh anybody round about</p> <p>1937.</p> <p>1938. CP: So this helps you here, I mean to, through the day?</p>	<p>Purpose/plans for future.</p> <p>G</p>
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<p>Hospitalisation as imprisonment.</p> <p>Peer support.</p>	<p>1939.</p> <p>1940. P: Boredom, you know the, the heat's one thing, but the, the</p> <p>1941. boredom does get to you [mmm], a lot, I mean I've got my</p> <p>1942. computer, I've got books, magazines but even that you know</p> <p>1943. you still just get really, really bored [mmm] ... but ...</p> <p>1944.</p> <p>1945. CP: I see</p> <p>1946.</p> <p>1947. P: It's just one oh these things</p> <p>1948.</p> <p>1949. CP: And now ... you said you, you did mention the other time,</p> <p>1950. the, the other time that you said that when, when you're here</p> <p>1951. it's like a holiday in prison, do you remember?</p> <p>1952.</p> <p>1953. P: Yes, yes. Now that was said in jest about the prison bit ...</p> <p>1954.</p> <p>1955. CP: Yeah</p> <p>1956.</p> <p>1957. P: ... but it was more about the institution [mmm] ...</p> <p>1958. institutionalisation [mmm, mmm], em but it, you know to a</p> <p>1959. certain extent it is, you know 'cause things are regimented</p> <p>1960. [mmm] you, you know you get woken up at such a time, you</p> <p>1961. get your medicine at such a time, you get fed at such a time ...</p> <p>1962. the visiting hours are at a such a time [mmm], but it was the</p> <p>1963. same when I was off-shore, I work off-shore for 10 years and,</p> <p>1964. you know you're in a confined space and we used to joke that it</p> <p>1965. was like doing prison [mmm] when you were work, working</p> <p>1966. off-shore, you know you were working for 12 hours and then</p> <p>1967. you were in your room for 12 hours</p> <p>1968.</p> <p>1969. CP: Mmm, so yeah. And how is, how is it now that you are in</p> <p>1970. a 4-bed ward? And you have, you're like with other ... ?</p>	<p>He is taking it back.</p> <p>Institutionalisation: a routine.</p> <p>D</p> <p>Hospital life and working off-shore.</p> <p>D</p> <p>Illness connects them.</p>
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Peer support.	<p>1971.</p> <p>1972. P: It's, it's funny, I mean I've never been the most sociable of,</p> <p>1973. of, of people, you know I like to keep myself to myself, em ...</p> <p>1974. but because we're all in the same situation, you know you</p> <p>1975. automatically get on wi people, it's very hard to find somebody</p> <p>1976. in here that you're going to fall out with 'cause they're all in the</p> <p>1977. same boat [mmm], eh OK some people are at different stages</p> <p>1978. or they'll have slightly different ...</p> <p>1979.</p> <p>1980. CP: Yeah</p> <p>1981.</p> <p>1982. P: ... eh conditions [mmm], but you know we, we're all the</p> <p>1983. same and, yeah, I mean ... there's a guy just moved in yesterday</p> <p>1984. [m-mmm], I'm getting on great wi him and, yeah it's, it's, it's</p> <p>1985. just amazing how you, you just start talking to him and it, it's a</p> <p>1986. good, good to get other people's perspectives [mmm], of how</p> <p>1987. they're coping, you know with their eh conditions</p> <p>1988.</p> <p>1989. CP: So ... what did you hear that you found, I mean ... ?</p> <p>1990.</p> <p>1991. P: E-m ... I can't think of anything ...</p> <p>1992.</p> <p>1993. CP: Like in specific...</p> <p>1994.</p> <p>1995. P: ... specific just now but it's, it's just sharing [mmm], you know</p> <p>1996. sharing your experiences, you know [mmm], eh like oh "I was</p> <p>1997. on such and such a drug and it made me really ill, but ...", well I</p> <p>1998. was on the same drug but I was OK with it and ... and "oh I, I,</p> <p>1999. you might be going onto this drug, eh just watch because you</p> <p>2000. might have this side-effect", you know things like that, just sort</p> <p>2001. oh sharing experiences is, is, is really quite important I think</p> <p>2002. [mmm]. And especially eh the first, last year when I was in for</p>	<p>T</p> <p>Peer support.</p> <p>G</p> <p>It's like he wants confirmation.</p> <p>Sharing the experience of treatment and side effects as source of support.</p> <p>T</p> <p>Peer support.</p> <p>He describes how information is different when coming from patients v. staff.</p>
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<p>Value of information experienced.</p>	<p>2003. the first time, you know it was all totally new to me, eh ... and it</p> <p>2004. was really, really good, some of the people that had been there</p> <p>2005. for months and months or even years, explaining you know</p> <p>2006. that, how the treatments would work, what to expect, eh you</p> <p>2007. know it was really great. You know the doctors and the nurses</p> <p>2008. are great but they can, they only tell you so much and there's</p> <p>2009. certain things obviously they can't tell you, whereas a patient</p> <p>2010. has got no ... eh, what's the word? [sighs] ... they're not bound</p> <p>2011. by any sort of secret, eh not secrets, but you know eh</p> <p>2012. confidentiality [mmm], so they can tell you a lot oh things that</p> <p>2013. you know the doctors and nurses are not allowed to tell you, if</p> <p>2014. you know what I mean</p> <p>2015.</p> <p>2016. CP: Yeah em ...</p> <p>2017.</p> <p>2018. P: Not, not ...</p> <p>2019.</p> <p>2020. CP: ... no, no, no, no ...</p> <p>2021.</p> <p>2022. P: ... particularly ...</p> <p>2023.</p> <p>2024. CP: ... no, no, no, no ...</p> <p>2025.</p> <p>2026. P: ... serious things ...</p> <p>2027.</p> <p>2028. CP: ... yeah, I, I ...</p> <p>2029.</p> <p>2030. P: ... you know but ...</p> <p>2031.</p> <p>2032. CP: ... I understand what you are saying, em do you find</p> <p>2033. yourself, I mean do you, are you doing the same thing now</p> <p>2034. that you have some experience ...</p>	<p>There is a sense that information coming from staff is limited.</p>
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<p>Leukaemia hard to make sense of</p> <p>Stoicity/acceptance.</p> <p>Acceptance.</p> <p>Trust in healthcare professionals.</p>	<p>2035.</p> <p>2036. P: Yeah, yeah ...</p> <p>2037.</p> <p>2038. CP: ... with the new ones?</p> <p>2039.</p> <p>2040. P: ... m-mmm. Well that's what it's all about, to share the</p> <p>2041. knowledge you know. Em, like when you see some people that</p> <p>2042. are in for the first time just giving them a, a boost, you know to</p> <p>2043. ...</p> <p>2044.</p> <p>2045. CP: Mmm</p> <p>2046.</p> <p>2047. P: ... everything's fine, you're in the best ward, you know ...</p> <p>2048. you're getting the best treatment here, eh ... just, yeah, just</p> <p>2049. helping each other out</p> <p>2050.</p> <p>2051. CP: Mmm, good. So ... to wrap the entire thing up ...</p> <p>2052.</p> <p>2053. P: M-mmm</p> <p>2054.</p> <p>2055. CP: ... when we started 3 weeks ago and I asked you what</p> <p>2056. does leukaemia mean to you, you said "I don't really know",</p> <p>2057. do you know now?</p> <p>2058.</p> <p>2059. P: [sighs] Not really, no ... it's ... it's just something that's</p> <p>2060. happened to me, em ... [laughs] ... I, I, I really can't ... I, I, I really</p> <p>2061. can't eh think, it's just one of those things ... em ... it's just</p> <p>2062. happened and I have to deal with it</p> <p>2063.</p> <p>2064. CP: Mmm</p> <p>2065.</p> <p>2066. P: It doesn't, it doesn't particularly frighten me [m-mmm], em, I</p>	<p>He is the supporter now.</p> <p>Efforts to make sense.</p> <p>Leukaemia is hard to make sense.</p> <p>Stoicity – acceptance.</p> <p>T</p> <p>Faith/trust in doctors.</p> <p>Leukaemia can be treated.</p> <p>It can happen to anyone.</p>
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<p>Leukaemia a nasty disease.</p> <p>Leukaemia with unknown cause – hard to make sense of.</p> <p>Stoic acceptance.</p> <p>Impact of leukaemia on self:</p>	<p>2067. know what the consequences can be [m-mmm], but ... you</p> <p>2068. know I have faith, I have faith in eh the doctors that what</p> <p>2069. they're doing is the right thing. Eh and, and things seem to be</p> <p>2070. looking good, you know things, the chemo seems to be working</p> <p>2071. and ... that's it, it's just ... [sighs] ... it's just a, I, I don't know, you</p> <p>2072. know people catch all sorts of diseases, I've just caught a, a</p> <p>2073. particularly nasty one</p> <p>2074.</p> <p>2075. CP: You mean that you don't blame anyone</p> <p>2076.</p> <p>2077. P: Oh no ... I don't blame anyone no ...</p> <p>2078.</p> <p>2079. CP: Mmm</p> <p>2080.</p> <p>2081. P: ... no – <i>how can I blame anyone?</i></p> <p>2082.</p> <p>2083. CP: Mmm</p> <p>2084.</p> <p>2085. P: I can't blame myself for having this. Em, I don't know how it</p> <p>2086. was caused [mmm], could be a multitude of things [mmm], em</p> <p>2087. so no I ... "blame" is, is something that I've never thought</p> <p>2088. about, no</p> <p>2089.</p> <p>2090. CP: M-mmm</p> <p>2091.</p> <p>2092. P: Like I, I think I did say earlier you know I, I, I was a heavy</p> <p>2093. smoker [mmm, yes], and em ... when I, when I first found out I</p> <p>2094. had "a" cancer of some description I blamed that on myself for</p> <p>2095. being a heavy smoker, <i>knowing the risks</i> [mmm], but then I was</p> <p>2096. told that my smoking had nothing to do with actually getting</p> <p>2097. leukaemia so, no I, I don't blame anybody or anything for it, it's</p> <p>2098. just one of these things</p>	<p>Leukaemia a nasty disease.</p> <p>Leukaemia with unknown cause.</p> <p>A number of different things.</p> <p>T</p> <p>Initially, there was the possible cause of smoking → after clarifying that the cause is unknown → stoic acceptance</p> <p>D</p> <p>T</p> <p>Impact of leukaemia on personhood. A changed <u>better</u> person/version of him.</p>
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<p>Patient as expert.</p>	<p>2163. plans for the future and [laughs] ... I've had to cancel them now 2164. because I'm back inside, which was a bit of a disappointment, 2165. but ... hey ho 2166. 2167. CP: Mmm. So what's next ... in terms of your treatment now? 2168. 2169. P: Well I'm in, that's me ... 2170. 2171. CP: For a second time 2172. 2173. P: ... that, that's me sort of in my cycles now of the, the chemo 2174. [m-mmm], and that's got to go for, well it's going to be a 2175. couple oh months anyway [mmm], and I think it's 5, 5 cycles, 2176. I'm going through 4-cycles and each one's 5 days [m-mmm], eh 2177. so all I'm thinking about just now is getting through that em 2178. and going into remission and with my last eh bone-marrow it 2179. seems that that is happening ... 2180. 2181. CP: M-mmm 2182. 2183. P: ... eh once I do that then I'll have to think about my bone- 2184. marrow transplant, but I'm not thinking about that just now, all 2185. I'm concentrating on is getting through my chemo and having 2186. that sort oh work and then I'll deal with the bone marrow 2187. transplant ... 2188. 2189. CP: When it comes 2190. 2191. P: ... afterwards [mmm], yeah 2192. 2193. CP: And have your siblings been tested? 2194.</p>	<p>Patient as expert.</p>
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<p>Patient as expert.</p>	<p>2195. P: They have, the results aren't back yet ...</p> <p>2196.</p> <p>2197. CP: OK</p> <p>2198.</p> <p>2199. P: ... em ... so just have to wait and see</p> <p>2200.</p> <p>2201. CP: Mmm</p> <p>2202.</p> <p>2203. P: I mean it would be great if one of them is a match, obviously</p> <p>2204. it makes things so much simpler ...</p> <p>2205.</p> <p>2206. CP: Yeah</p> <p>2207.</p> <p>2208. P: ... eh and quicker as well because I was told you know it</p> <p>2209. could possibly be years to find, before they, they actually get a</p> <p>2210. match for me [m-mmm], <i>but</i> they can keep, keep me going by</p> <p>2211. actually using my own stem cells [m-mmm] eh and sort oh</p> <p>2212. cleaning them up and putting them back in but you know</p> <p>2213. that's, that's only a stop gap [mmm] method because eh,</p> <p>2214. because I'm missing part of my immune system [mmm],</p> <p>2215. leukaemia's ...</p> <p>2216.</p> <p>2217. CP: So you were talking ...</p> <p>2218.</p> <p>2219. P: ... always going to come back</p> <p>2220.</p> <p>2221. CP: ... you were talking about the possibility of having, you</p> <p>2222. know more than one bone marrow transplants because even</p> <p>2223. the one from, from your cells, it's supposed to be a bone</p> <p>2224. marrow transplant ... mmm</p> <p>2225.</p> <p>2226. P: So, yeah ... but ...</p>	<p>Patient as expert.</p>
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<p>Leukaemia treatable.</p> <p>Being hopeful.</p>	<p>2227.</p> <p>2228. CP: I mean if, if you don't get a donor very soon and you, I don't know ...</p> <p>2229.</p> <p>2230.</p> <p>2231. P: Yeah I think that's ...</p> <p>2232.</p> <p>2233. CP: ... is this, is this what you're saying...</p> <p>2234.</p> <p>2235. P: ... I think that's what it is, it's ... you know if they, if they can't</p> <p>2236. get a, a match then they'll harvest my own and put it in, but</p> <p>2237. like I say I'm always going to get the leukaemia coming back</p> <p>2238. [mmm], eh wi that method, but it's ... it's treatable [mmm], you</p> <p>2239. know so it should keep me going until I do get a, a, a match</p> <p>2240. somewhere ... but you know, fingers crossed it'll be sooner</p> <p>2241. than later but ...</p> <p>2242.</p> <p>2243. CP: Yeah</p> <p>2244.</p> <p>2245. P: ... I've, I'm quite positive about you know ... I'm not going to</p> <p>2246. just keel over ...</p> <p>2247.</p> <p>2248. CP: Yeah</p> <p>2249.</p> <p>2250. P: ... in 6 months' time, sort of thing, you know there is a light</p> <p>2251. at the end of the tunnel</p> <p>2252.</p> <p>2253. CP: Mmm, mmm, and that's something that, I mean that's</p> <p>2254. different from your first, first encounter with leukaemia with</p> <p>2255. your dad, I mean that's quite different isn't it?</p> <p>2256.</p> <p>2257. P: I think everybody knew that by the time my dad had</p> <p>2258. leukaemia he had other ...</p>	<p>D</p> <p>Leukaemia can be treated.</p> <p>T</p> <p>G</p> <p>There is hope. He thinks he is in a dark tunnel.</p> <p>Separating the two experiences: he was a different case than his father.</p> <p>Comorbidity.</p>
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<p>Health-illness perceptions.</p>	<p>2259.</p> <p>2260. CP: Problems</p> <p>2261.</p> <p>2262. P: ... he, he had other problems and I think we all kinda knew</p> <p>2263. that he ...</p> <p>2264.</p> <p>2265. CP: He wasn't ...</p> <p>2266.</p> <p>2267. P: ... he was not really going to survive</p> <p>2268.</p> <p>2269. CP: Mmm. But, so you don't think that it was actually</p> <p>2270. leukaemia that ... you know ...</p> <p>2271.</p> <p>2272. P: It didn't actually kill him, no ...</p> <p>2273.</p> <p>2274. CP: Mmm</p> <p>2275.</p> <p>2276. P: ... it was something else that killed him ... <i>but</i> if it hadn't</p> <p>2277. been for that, what happened was he had a fall and he had a</p> <p>2278. massive eh trauma to the back oh his head and that's, that's</p> <p>2279. what actually killed him, but had he not had that I think he ...</p> <p>2280.</p> <p>2281. CP: You think anyway ...</p> <p>2282.</p> <p>2283. P: ... he, I think we're, everybody's sort of of the opinion that he</p> <p>2284. would have eh died of the leukaemia</p> <p>2285.</p> <p>2286. CP: Mmm</p> <p>2287.</p> <p>2288. P: But I see that as a totally different ...</p> <p>2289.</p> <p>2290. CP: Different</p>	<p>T</p>
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<p>Being hopeful.</p>	<p>2291. 2292. P: ... circumstance to, to my, my own eh condition 2293. 2294. CP: Mmm 2295. 2296. P: ... you know 'cause I'm relatively healthy, you know I haven't 2297. got any major sort oh eh health problems em, so, no I, I, I don't 2298. see that I'm going to end up like my dad, no 2299. 2300. CP: Good. Be positive 2301. 2302. P: M-mmm, m-mmm 2303. 2304. CP: Well actually I don't think I have anything else to ask you, 2305. if you have anything else to add or, you know ... 2306. 2307. P: I can't really think oh anything ... 2308. 2309. CP: That has been brilliant ... 2310. P: M-mmm, oh good 2311. CP: ... really good to know and I'm going to turn this em ... 2312. [end of tape] 2313. 2314. 2315. 2316. 2317. 2318. 2319. 2320.</p>	<p>Hopeful.</p>
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